University of Alberta

# The Silent North: A Case Study on Deafness in a Dene Community

By

Heather Evelyn Castleden ©

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Master of Education

in

Adult and Higher Education

Department of Educational Policy Studies

Edmonton, Alberta

Spring 2002

National Library of Canada
Acquisitions and Bibliographic Services
395 Wellington Street
Ottawa ON K1A 0N4
Canada

Bibliothèque nationale du Canada
Acquisitions et services bibliographiques
395, rue Wellington
Ottawa ON K1A 0N4
Canada

*Your file Votre référence*

*Our file Notre référence*

The author has granted a non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of this thesis in microform, paper or electronic formats.

The author retains ownership of the copyright in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

L'auteur a accordé une licence non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de cette thèse sous la forme de microfiche/film, de reproduction sur papier ou sur format électronique.

L'auteur conserve la propriété du droit d'auteur qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

0-612-69660-X

Canada

University of Alberta

Library Release Form

Name of Author: Heather Evelyn Castleden

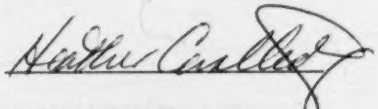
Title of Thesis: The Silent North: A Case Study on Deafness in a Dene Community

Degree: Master of Education

Year this Degree Granted: 2002

Permission is hereby granted to the University of Alberta Library to reproduce single copies of this thesis and lend such copies for private, scholarly, or scientific purposes only.

The author reserves all other publication and other rights in association with the copyright in the thesis, and except as hereinbefore provided, neither the thesis nor any substantial portion thereof may be printed or otherwise reproduced in any material form whatever without the author's prior written permission.



48 Whitehall Crescent
St. Albert, Alberta T8N 3G4

Date: November 21, 2001

University of Alberta

Faculty of Graduate Studies and Research

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled *The Silent North: A Case Study on Deafness in a Dene Community* submitted by Heather Evelyn Castleden in partial fulfillment of the requirements for the degree Master of Education in Adult and Higher Education.

Dr. Stan Wilson

Dr. Peggy Wilson

Dr. Paula Brook

Dr. Owen Beattie

Date: Nov. 20/2001

## Thesis Dedication

I would like to dedicate this thesis to Anne and the members of the First Nation who worked with me on this inquiry. Their participation, as reflected in their stories, clearly indicates their commitment to improving the supports and services available to families with deaf children across the North. This study would not have occurred without their collaboration.

**Abstract**

This study explores a northern Dene community's response to a particular health issue: deafness. Using a case study approach, the study examines deafness from a cultural perspective rather than from a pathological framework. Through the use of interviews and observations, family, community members, leaders, and professionals explored the transitions of self and knowledge as they critically reflected on how their perceptions towards deafness reshaped their paradigms and redefined their relationships within the community.

Linkages between northern communities and the health profession are needed in terms of providing culturally relevant materials, services, and resources that are responsive to each community's particular context. The implications of this research project are intended to open the channels of communication in terms of holistically addressing the health needs of northern communities, needs that have traditionally fallen on deaf ears.

**Acknowledgements**

I would like to thank each participant for your willingness and courage to share your stories with me. Without you, this study would not have been possible. I would very much like to thank the Chief and Council and the Elders' Committee for your support of this study. I especially appreciated the questions asked of me as you challenged me to think about my motives, goals, and methods.

I would also like to thank community members for your friendship, support, teaching, humour, patience, camaraderie, laughter, stories, singing, guitar-playing on cold winter nights, sharing your food, sharing your homes, sharing your knowledge, and making me feel welcome.

I would like to thank Dr Peggy Wilson and Dr Stan Wilson for your guidance and wisdom during my graduate program, for your patience while I was "madly off in all directions", and for your encouragement when I needed it most. I would like to thank Dr Paula Brook for your friendship, fabulous cookies, adventures, and of course, your support of my learning in adult education. I would like to thank Dr Owen Beattie for your willingness to critique the study and for sharing your insights. I would also like to thank Dr Joe Kaufert for your ongoing support and consistent interest in my academic development.

I would like to acknowledge the financial support provided through a Northern Scientific Training Program Grant from the Department of Indian Affairs and Northern Development with the Canadian Circumpolar Institute at the University of Alberta. I would also like to acknowledge the financial support provided through a Province of Alberta Graduate Scholarship from the University of Alberta.

I want to thank my family for your constant love and moral support – you have been and continue to be a most excellent fan club! I want to thank my mum and dad for your guidance as well as your active involvement in transcribing, reading, and editing this thesis (as well as your aeroplan points so that I could return to the community and report my findings!).

Finally, I want to thank Jay, my lifelong partner and best friend. You have made never-ending concessions and compromises so that I could complete this study. Most importantly, you have given me unconditional love and encouragement, both of which have made this thesis possible.

## Table of Contents


**Chapter One: Introduction**

Introduction 1
Background and Overview 1
Framework 2
My Self in Relation to the Research 2
Research Question and Methodology 4
Significance of the Study 5
Defining Categories 6
Organization 7

**Chapter Two: Conceptual Framework – Deafness as a Cultural Identity**

Introduction 9
Medical Model Versus Cultural Framework 9
Pre-Contact: Deaf People and Signed Languages in North America 12
Historical Perspectives on American Sign Language 13
History of Manual Codes of English 14
The Language Debate 15
The Residential School Experience 16
Providing a Context: Disabilities in the North 17
Contemporary Health and Education Services for Aboriginal People in the North 17
Hearing Loss in the Circumpolar North 18
Role of Aboriginal Parents in Children's Education and Health 19
Access to Support Networks for the Deaf in the North 21
Social Networks and Coping Among Parents with Deaf Children 22
Familial Support Versus External Support 23
Hearing Parents Supporting Hearing Parents 24
Deaf Adult Role Models 24
Extended Family Dynamics 25
Early Language Acquisition 25
Stress and Coping Among Minority Parents of Deaf Children 27
Conclusion 28

**Chapter Three: Methodology and Setting**

Introduction 29
Defining Case Study Research 29
Validity of Case Study Research 32
Methods 33
Considerations 35
Non-Aboriginal Researchers in Aboriginal Communities 36
Permission to Conduct the Study 38
The Setting 39
The Participants 41
Developing Rapport 42
Informed Consent, Confidentiality, and Accuracy 44

Limitations 45
Conclusion 45

**Chapter Four: Northern Voices**
Introduction 47
Making Enquiries 47
A Mother's Reflections 49
Reflections of the Extended Family 56
Auntie Carolin (Paternal Aunt) 56
Auntie Margaret (Maternal Aunt) 58
Joe (Paternal Step-Grandfather and Community Elder) 60
The Professional Perspective 63
Beth: An Audiologist's Account 63
Tarah: The Community Health Representative 70
Barb: A Social Work Perspective 74
Jennifer: Perspective from the Education Administration 75
George: A Community Wellness Perspective 78
Conclusion 81

**Chapter Five: Analysis of the Data**
Introduction 82
Themes from the Literature 82
Parental Perspective: Themes Emerging from the Data 85
Perspectives from the Extended Family: Themes Emerging from the Data 88
Community Perspectives: Themes Emerging from the Data 89
Professional/Medical/Social Support Perspective: Themes Emerging from the Data 90
Conclusion 94

**Chapter Six: Conclusions and Recommendations**
Introduction 95
Summary of the Study 95
Implications 97
Community Recommendations 98
Further Recommendations 101
Deafness in the North: Creating Awareness 101
Theoretical Reflections 102
Methodological Reflections 102
Critical Reflections 104
Reporting Back 105
Conclusion 106

**Bibliography** 107

**Tables**
Table 1 96

**Diagrams**
Diagram 1 43

**Appendices**
Appendix 1: Modes of Communication

Appendix 2: Definitions of Case Study Research

Appendix 3: Ethics Review and Consent Forms

Appendix 4: Aurora Research Institute License

## Chapter One

## Introduction

*What matters deafness of the ear when the mind hears?*
*The true deafness, the incurable deafness, is deafness of the mind.*
*-Victor Hugo*

### Introduction

This thesis is a case study of collaborative community-based research regarding a Dene community's response to having a deaf child in their community. The thesis covers the initial period of time the child was in the community as well as later critical reflections by community members on how their perceptions towards deafness reshaped the way they viewed the world and redefined their relationships within the community. As the setting is a Dene community in the Northwest Territories and I am of Euro-Canadian descent, the inquiry is a cross cultural experience for me and for the community of Ehchuse[1] who supported the study.

### Background and Overview

This study has been conducted with the intent of serving a multitude of people living over a wide geographic area of northern Canada belonging to distinct cultural groups: Dene and Deaf, who are inextricably linked to one another by a singular issue – deafness. Using the experiences of one Dene community in the Northwest Territories, I have investigated whether there was the support and access to information needed to address the issues that are fundamental to raising a child who is

[1] Ehchuse is the Dene community that participated in this study. In an effort to protect the people who participated in this study, pseudonyms have been given to the community name and the names of all of the participants.

deaf in the North. Determining the extent of availability, accessibility, quality, and distribution of educational resources and social support regarding deafness as well as degree of user satisfaction within this northern community are key aspects of the study.

Ninety percent of deaf children are born to hearing parents and most of these parents have had little or no exposure to deafness prior to the medical diagnosis (Frazier-Maiwald & Williams, 1999; Lane, 1999; Magnuson, 2000; Marschark, 1997; Poon, 1998; Sacks, 1989). As with any event that forces people to cope with a series of atypical lifestyle challenges, having a deaf child requires a great deal of learning. Initially, parents and extended family experience a steep learning curve regarding the pathological, philosophical, psychosocial, and cultural issues regarding deafness. Community members are also confronted with a learning challenge regarding communication, attitudes, acceptance, and understanding.

The consequences of unavailable or inadequate educational materials on deafness are severe, including delays in deaf children's language, social, cultural, and cognitive development, which will be further elaborated on in the next chapter. For parents of deaf children living in remote communities, it is vital to have immediate access to useful materials about deafness, as healthcare practitioners may not be directly available. Healthcare professionals have an obligation to care for the well being of their patients. In cases of hearing loss, they have an added charge of educating people about the significant decisions that are constituent with hearing loss and the implications of

those decisions. Accurate and culturally relevant material must be immediately available.

The need to have complete access to resources in order for parents to make informed, educated decisions is fundamental in terms of a deaf child's welfare. There is an enormous amount of information that individuals, families, and community members may receive in a short period of time. The key here is *may receive*. Because there are opposing philosophical views about deafness, stakeholders may receive inadequate or incomplete information. The information they receive will be dependent on who they connect with for expert advice. Further, "experts" are not always easily accessible or readily available, especially in rural and northern areas. This research project documents one community's situated response to deafness and identifies gaps in information as well as in availability and accessibility to that information.

**Framework**

The health field has historically situated deafness in a pathological[2] framework and continues to address deafness from this perspective. However, the North American deaf population has identified itself as a Deaf community[3] – a linguistic and cultural

[2] The pathological framework, also known as the medical model, identifies deafness as a disability. Lane (1999) "maintains that the vocabulary and conceptual framework our society has customarily used with regard to deaf people, based as it is on infirmity, serves us and the members of the deaf community less well then a vocabulary and framework of cultural relativity" (p. 19).

[3] The term community has been used here in accordance with how the Deaf population interprets community, which is based on Lane's definition. Lane (1999) states that "membership in the deaf community is not decided by diagnosis; in fact, it is not decided at all....various culturally determined behaviors, and foremost among them language, reveal whether or not an individual belongs to a language minority or not" (p. 20).

minority. This thesis will consider deafness from a cultural framework[4] rather than from a pathological framework. Both of these frameworks will be described in the following chapter, which also covers a review of the literature.

**My Self in Relation to the Research**

I am of English and Scottish heritage. I was born in the Northwest Territories and I have always had a strong desire to re-establish a connection to that northern space and place, hence my interest in conducting a study in the North. My parents spent several years in northern and Aboriginal communities before and after I was born. They made many friends, as did I, from these communities and so I grew up with Aboriginal and international friends, both children and adults. Although the context of my life experience has been grounded in white, urban, middle class, I feel that in many ways, my experience has not necessarily been the norm. My parents have instilled in me a sense of respect for diversity and difference, particularly in the cross cultural context.

I decided to engage in a study on deafness as a result of several years of involvement in the Deaf community, first as a sign language student and interpreting student in Vancouver learning about the language, culture, history, and the community of the Deaf, followed by seven years working for the Winnipeg Deaf community as an English and American Sign Language interpreter. I currently teach students in an

[4] Although there is no standard definition of culture, most alternatives incorporate the Boasian assumption as in the case of Bates and Plog's application, which I have employed in this study. Culture: The system of shared beliefs, values, customs, behaviours, and artifacts that the members of society use to cope with their world and with one another, and that are transmitted from generation to generation through learning (p. 7).

interpreter training program in Edmonton. I have been involved with the Deaf community first as a student, and later as a friend, a professional, and an advocate.

I chose to investigate a First Nation's response to deafness after having pursued a Bachelor's degree in Cultural Anthropology and Native Studies. As I progressed academically, I began to recognize similarities between the Deaf community's and the Aboriginal population's experience of oppression[5] at the hand of the dominant society. While still in Winnipeg, I began to ask friends who were both Deaf and Aboriginal about their experiences and began to recognize what seemed to be a pattern of assimilation[6]. The hearing population has attempted to force the Deaf community to assimilate; the Euro-Canadian population has attempted to force First Nations to assimilate, so too, I hypothesized, has the Deaf community followed a pattern of assimilation in that Deaf members shed their original identity. Having arrived at this hypothesis, I began to shape this thesis. However, rather than focusing on one Deaf

---

[5]Kaiser (1990) states that "oppression is the 'systematic mistreatment of one group of people by another group of people, in which there is an imbalance of institutionalized power'. Systematic mistreatment refers to the methodical and widespread way in which psychological, physically violent, and verbal forms of abuse are directed at particular groups targeted for oppression. It often appears to happen to one person alone, but actually occurs on a societal and institutionalized level to all people belonging to that same targeted group. An imbalance of institutional power is an essential part to this definition of oppression." Oppression, in terms of Aboriginal peoples, refers to the European attempts to Christianize, 'civilize', colonize, and control Aboriginal peoples. The Deaf community has been oppressed by the dominant hearing majority in terms of denying the existence of a linguistic and cultural identity as well as access to information and political autonomy.

6 What is meant by assimilation is that both the hearing population and Euro-Canadians have tried to absorb and integrate the Deaf community and Aboriginal peoples respectively into the dominant society, attempting to deny each group of its own identity and distinct status. Armitage (1995) summarizes the policy of Aboriginal assimilation into Euro-Canadian society: "it is traced through five principal phases: a period of initial contact when the power relationships necessary to carry out the policy were established; a period in which the policy was passive and in which the aboriginal people were expected to die out or merge with the immigrant populations; a period of aggressive policy in which specific social policies were introduced to suppress aboriginal institutions; a period of integration in which it was thought that the policy could be achieved through disregarding the aboriginal existence; and the present period in which the policy is being reversed as aboriginal people re-establish control of their own social policy."

individual's experience of living in a northern Dene community, I chose to explore the community's response to having a deaf child in the community. The scope of issues that I wanted to investigate required an interdisciplinary approach that drew on a number of disciplines and specializations. To limit the study to the confines of one discipline would have been inadequate. The challenges encountered working as an external researcher in a cross cultural environment are also addressed.

**Research Question and Methodology**

In this study, I attempt to address some of the issues surrounding family and community decisions regarding a community member who is deaf, based on professional and social support available to this individual. I also address how the study shaped my sense of self as a researcher and how the study has altered my perceptions regarding "best medical and educational practices" for northern Aboriginal people who are deaf.

This cross cultural case study has focused specifically on a cultural perspective towards deafness. I discuss the various perspectives of people affected by deafness in different ways in a Dene community in the Northwest Territories. Through the use of interviews with family members, community members, community leaders, and professionals as well as participation in Elders' committee meetings and Chief and Council meetings, I have documented how a deaf child has had an impact on a northern Dene community. I have kept a journal in which I have recorded my experiences, thoughts, and feelings as a researcher in this cross cultural setting (unfortunately this

journal was stolen when I returned to Edmonton and I am not able to contribute this portion of my experience to the written part of this study).

My involvement with the Deaf community and my academic pursuits in Native Studies were the starting point that led to the question that guided this study: **"What is this Dene community's situated response to having a deaf child in the community?"** I explored the transitions of self and knowledge as community members critically reflected on how their perceptions towards deafness reshaped their paradigms[7] and redefined their relationships within the community. I also included my own critical reflections regarding my changing perceptions towards northern community decisions in terms of deaf members as well as my understanding of community-based research. In so doing, the resulting thesis has combined my experience of being an investigator engaged in community-based research with a cooperating community and the original research question. The research then is defined as a critical story as it includes discussion regarding the relationship between the researcher and the participants (Park, 1997).

**Significance of the Study**

Westerners have often described the North as an inhospitable and vast wasteland that is not fit to live in. However, to a small but steadfast population, the North has not

[7] I have used the term paradigm based on the following definition: "Researchers define paradigm as 'a world view, a general perspective, a way of breaking down the complexity of the real world (Patton, 1975, p. 9)' further a paradigm is a constellation of theories, questions, methods, and procedures, which share central values and themes. This constellation, which develops in response to historical and cultural conditions provides a conceptual framework for seeing and making sense of the social world we create and live in (Popkewitz, 1984). A paradigm provides a place to stand from which to view reality" (Maguire, 1987, p. 11).

only provided the necessities of life but it has provided the backdrop for this population to develop and maintain a culturally rich and diverse way of life. Despite the frequently held belief that Northerners were disease and illness free prior to European contact, this population did have health problems and illness[8]. However, there is a lack of physical evidence and therefore only sketchy epidemiological inferences can be made about pre-contact health (Waldram, Herring, & Young, 1995). Contact with Europeans led to exposure of new illness and disease often with devastating results in terms of morbidity and mortality. Current health conditions in the North have stemmed from a variety of social, economic, political, geographical, and environmental factors putting Northerners at greater risk of illness than their neighbours in southern Canada (O'Neil, Reading, Bartlett, Young, & Kaufert, 1999).

Determining the relevancy of this particular research topic is based, to a certain extent, on latent need. Statistics indicate that less than ten percent of deaf children are born to deaf parents. This means that over ninety percent of parents have had little or no exposure to deafness and the issues that stem from it. In southern Canada, awareness, supports, and resources are still lacking. Therefore, it would not be unrealistic to assume that the northern situation is even more dismal. Moreover, the incidence of hearing loss in the North is higher than in southern Canada.

The Aboriginal population makes up the majority of the population in the Canadian North. Given that Aboriginal people bear a disproportionate burden of illness

[8] For a discussion on pre-contact disease and illness in Canada see Waldram, Herring, and Young (1995).

in Canada (O'Neil, Reading, Bartlett, Young, & Kaufert, 1999), the focus of this thesis has been on the condition of a particular "health" issue in one First Nations community in the Northwest Territories. The Health Bulletin (1999) documents the Assembly of First Nations' call for a comprehensive child health framework:

> First Nations leadership has identified the need for a comprehensive and collaborative approach to address children's health, given the special relationship that First Nations children have with the Government of Canada, as outlined in the Canadian Constitution....The AFN recommends a combination of policy development and health promotion initiatives are needed in [several areas including] *disabilities*;* develop a strategy to *provide support for families and communities*, particularly at schools for children with disabilities; *address the inadequacies and absence of support services for disabled children; address needs specific to northern and remote communities*; increase access to medical devices. (p. 10-11, note: italics do not appear in the original text)
>
> *note: deaf children would fall under the rubric of support services for disabled children as understood by the general population and government.

There is, in Canada, a recognized need for improved support services for families and communities with special needs as well as the particular demands of northern communities in terms of access to those services. At the time of this study, the Northwest Territories Council for Disabled Persons conducted a quantitative needs assessment across the Northwest Territories in an attempt to determine the statistical composition of people living with disabilities and a characterization of their needs. Further research on the above noted health issues is urgently needed to substantiate the call for these services.

The Deaf community, labelled as disabled by the medical field and the general population, has struggled to be recognized as a cultural and linguistic minority that is capable of deciding its own future and taking ownership for its actions. Deaf leaders have endeavoured to empower their members through education. Much has been written

on the subject of Deaf Identity[9], on the associated language debate as to whether ASL or Signed English should be the language of instruction for deaf children, on ethical considerations regarding surgical and genetic intervention, and about support for hearing parents of deaf children living in mainstream North America. Lacking in the literature is any discussion on the experience of hearing parents with deaf children living in rural/remote areas or the experience of Aboriginal parents with deaf children and the need to support their distinct First Nations identity. This study explores a Dene community's response to having a deaf child in the community. The primary focus of the inquiry is to compare the services and social supports available to northern communities versus those available in southern Canada by sharing the story of one family's journey into the labyrinth of issues surrounding deafness.

**Defining Categories**

**"Deaf" versus "deaf"**

By capitalizing the word "Deaf", the Deaf community has, in essence, reclaimed a prescribed label that has historically had negative connotations associated with it (i.e. "deaf and dumb"). For the purpose of this thesis, I will capitalize the word "Deaf" when referring to the Deaf community, which is a group identifying themselves as members of a cultural and linguistic minority. In all other cases, I will use "deaf" as I am not in a position to ascribe member status.

Several factors determine a person's status within the Deaf community. To gain membership in the Deaf community in Canada, one must identify oneself as being Deaf

[9] For further reading on Deaf Identity see Lane (1999), Cohen, (1995), Sacks (1989).

and use American Sign Language (ASL)[10] to communicate. Membership in the Deaf community is not determined by an individual's degree of hearing loss or by an audiologist's audiogram. Membership is based on various culturally determined behaviours. Foremost among these behaviours is language, which determines whether an individual belongs to the Deaf community (Lane, 1999). Not all individuals who are born deaf become members of the Deaf community. For example, a person who is born deaf, attends a hearing school, does not use an interpreter, relies on lip-reading or hearing devices (i.e. hearing aids), and only socializes with the hearing population does not identify himself or herself as a member of the Deaf community. Most likely, that individual subscribes to the label "hearing impaired".

Similarly, not all Deaf community members are born deaf. In fact, congenital or hereditary deafness is not entirely common. Many deaf children are born hearing and are post-natally deafened as a result of prolonged illness, infection, or through accidental causes. Still others become deaf later in life, usually as a result of accident, medicinal contraindications, or prolonged hearing damage (i.e. prolonged exposure to loud noises). For example, the Deaf president of Gallaudet University in the United States (the only Deaf university in the world) was not born deaf. He lost his hearing in a motorcycle accident as a young adult yet he embraced his new cultural and linguistic identity. Dr. Jordan is culturally Deaf and an important leader in the Deaf community.

[10] In the Deaf community, American Sign Language is commonly referred to as ASL and it will be referred to as such throughout this thesis.

Core versus peripheral status in the Deaf community is determined in terms of several indicators including whether one attended a residential school for the deaf, the "purity" of one's ASL, and whether one has Deaf parents or other Deaf family members. Additionally, the degree of hearing loss and whether residual hearing and speech is utilized does not necessarily define an individual's status in the Deaf community. Individuals with mild to moderate hearing loss may have core community member standing because of their active involvement in the community.

Furthermore, individuals who have grown up in a hearing environment and who subscribed to a hearing impaired label may, at some point, shed this original label, acquire ASL as a second language and become active members of the Deaf community. This phenomenon is relatively common as parents of D/deaf children decide against ASL and exposure to the Deaf community and opt for an oral/aural approach. As adults, these individuals may seek out the Deaf community for solidarity and fellowship.

**Aboriginal**

For the purposes of this thesis, I will use the term Aboriginal when referring to the original inhabitants of Canada. When referring to community members of Ehchoosay, I will use the term Dene as they are members of the Dene First Nation, which is the local Aboriginal government.

**Organization**

To tell this story, I have divided the thesis into six chapters. Chapter One has provided the background and rationale for the study as well as my personal relationship to the study. Chapter Two examines the theoretical framework that is used to situate the study and a review of related literature. Chapter Three examines the use of case studies as a qualitative research methodology and provides the circumstances under which I obtained permission to carry out the study, the setting for the study as well as the obstacles encountered regarding the initiation of this study. Chapter Four provides the venue to hear the voices that shape the story. Also included are my interpretations, though they are kept brief, in an effort to illuminate and enlighten, rather than scrutinize and analyze (Abramson, 1992). Chapter Five provides my interpretation of the various themes emerging from the data and an analysis of those themes. Finally, Chapter Six summarizes the previous chapters focusing on the key findings and implications of the research. I examine the challenges that surfaced and the learning that occurred while conducting the inquiry. This includes issues relating to the evolution of the research question, awareness of the interpersonal dynamics within the community, and an examination of my role as an external cross-cultural researcher. Community-based recommendations as well as my own are provided and areas for further study are identified. Concluding comments and reflections as well as a discussion of the implications and recommendations for further study are also presented in the final chapter.

## Chapter Two

## Conceptual Framework: Deafness as a Cultural Identity

### Introduction

This chapter addresses the theoretical framework used in this study. A review of the literature related to the framework for this study is also provided. The first half of the chapter provides a framework for situating deafness outside of the "disability" umbrella. Deafness, from the perspective of the Deaf community and its supporters, is seen not as a disability but as a cultural identity. It is from this framework that the study is conducted. A historical overview of the origins of contemporary American Sign Language (ASL) and the language debate regarding the language of instruction for deaf children are necessarily included for understanding the present conditions in Canada for the Deaf community. A brief description of the cultural identity of the Deaf follows.

Having established an understanding of deafness from a cultural framework, the second half of the chapter is devoted to a description of the services available to Aboriginal people in the North. An examination of how people living with deafness in the North manage their daily lives and accessibility to services is the fundamental issue addressed in this thesis. The role of Aboriginal parents in their children's health and education is examined in a broad manner. Finally, an appraisal of the available literature regarding the experiences hearing parents have when faced with the medical diagnosis of having a deaf child is shared, including the social support systems and issues that confront parents throughout the lifespan of their deaf children.

**Medical Model Versus Cultural Framework**

In recent years, the deaf population made its collective voice heard in terms of its condemnation of the medical label "hearing impaired". This geographically widespread cultural group has become politically active in vocalizing its identity as a linguistic and cultural minority, stepping out from beneath the umbrella of the disability movement. As a result of linguistic research, American Sign Language (ASL), the language of the Deaf in North America (excluding Quebec where the Deaf population uses an altogether different sign language), has been officially recognized as a true language with all of the grammatical structures, syntax, and semantics of spoken language. This linguistic and cultural minority identifies itself as Deaf (note the capitalization of the proper noun). The Deaf community is as rich in heritage, folklore, norms, mores, and traditions as are their French, Italian, Russian, or Chinese hearing counterparts. Unique to this community is the fact that most (90%) Deaf individuals are born into hearing families (Lane, 1999; Magnuson, 2000; Marschark, 1997; Poon, 1998; Sacks, 1989). Therefore the original linguistic and cultural identity of the individual may be French, Italian, Russian, or Chinese but ASL and membership in the Deaf community define the individual's assimilated linguistic and cultural identity.

Where the Deaf community sees a language difference, the medical profession views prelingual and congenital deafness and hearing loss as medical problems that need to be fixed (Frazier-Maiwald & Williams, 1999). The Deaf community as a linguistic and cultural minority is unlike disability groups. "The Deaf community has a distinctly different agenda [the aim of which is to gain acceptance of ASL and Deaf

culture]. Moreover, to be Deaf is not a disability in Deaf culture, and most members of the Deaf-World see no disability in their way of being" (Lane, 1999, p. xiii). Lane (1999) notes that most members of the Deaf community do not share their Deaf identity with their parents and that Deaf identity cannot be developed in a home where the family is hearing.

A former secretary-general of the United Nations has recognized that Deaf people are not a disability group but rather are a linguistic minority. By this recognition, Deaf people are afforded more respect (Lane, 1999). Reflection on the history of the Deaf in North America serves as a reminder of the initial existence of this cultural framework. Prior to 1880, hearing people viewed culturally Deaf people predominantly in terms of a cultural model. During this period, one needed to know the language of the Deaf community to teach Deaf children. Deaf and hearing educators, proficient in ASL, taught Deaf children using ASL as the primary mode of communication. Deaf adults played a prominent role in the education of Deaf children, which provided opportunities for total immersion in Deaf culture. However, in 1880, a European convention on Deaf education was held in Milan, Italy. At this meeting of mainly hearing educational administrators, a referendum was held regarding the mode of communication used to teach Deaf children. The overwhelming majority of hearing participants voted in support of removing ASL from the classroom and in favour of adopting oral/aural communication[11]. The outcome of that convention had a trickle-down effect throughout Europe and North America and by the turn of the century the

[11] Oral/aural communication relies on speech-reading strategies, reliance on residual hearing, and with technological developments, hearing aid devices and cochlear implants.

number of Deaf adults teaching in residential schools for the Deaf decreased drastically from over 80 percent down to less than ten percent of academic and support staff. Hearing teachers quickly embraced the oral/aural approach in residential schools and ASL lost its place as the primary language of instruction for Deaf children across the continent. Children were discouraged and/or punished for using ASL. Deaf people were effectually excluded from educating most Deaf children. However, the Deaf community has argued and continues to argue that Deaf people themselves should be the leaders in terms of discussion concerning the lives of Deaf children and Deaf adults and the roles of the professions that serve them. But the Deaf community has historically been excluded from – socially, by law, and by oppressive education policies and institutions. The guidance and advice from Deaf adults, which the parent of a newborn deaf child needs more than any other, is consistently excluded from the home and the clinic (Lane, 1999). "Their services as a language model for the deaf child are eschewed and the responsibility unconscionably given to the child's hearing mother, who cannot fulfill it" (Lane, 1999, p. 23).

Having addressed deafness from a cultural framework, a basic understanding of the causes and treatment of hearing loss (leading to deafness) from a medical perspective is necessary. Queen (2001) provides the following information:

> Hearing loss is divided into two types: conductive and sensorineural. Conductive hearing loss is due to a problem in the outer or middle ear, while sensorineural hearing loss is due to a problem in the inner ear or central nervous system. Causes of conductive hearing loss…include wax impaction, foreign bodies, tumours or infections of the outer ear, perforations of the eardrum, infections or persistent fluid in the middle ear, abnormalities of the middle ear bones, such as dislocation,

> erosion, fracture or fixation, cholesteatoma (skin trapped in the middle ear and/or mastoid), and otosclerosis (fixation of the third middle ear bone to the inner ear). All can be treated with medicines or surgery. Wax and foreign bodies are removed. Infections are treated with antibiotics and/or surgery. Tumours and cholesteatoma are excised. Persistent fluid is treated with middle ear ventilation tubes. Perforations, abnormalities of the middle ear bones, and otosclerosis are repaired. Sensorineural hearing loss…[has] many different causes and…in a surprising number of cases, the cause is never identified. Metabolic causes of hearing loss…include high blood pressure, high cholesterol, diabetes, thyroid disease, anemia, and calcium disorders. Autoimmune causes include rheumatoid arthritis, lupus, sarcoid, and other more rare disorders. Infectious diseases such as syphilis and meningitis may also cause hearing loss. Congenital causes of hearing loss result from abnormalities during fetal development. In most cases, hearing aids are the only treatment option, although surgery may help if the hearing loss is conductive. Noise exposure can lead to hearing loss and [it] may be temporary or permanent. The only treatment available is a hearing aid, if the hearing loss is severe enough. Presbyacusis is [a type of] hearing loss [and it is] due to aging. It affects the high frequencies first and then eventually all frequencies are involved. Again the only treatment available is a hearing aid, if the hearing loss is severe enough. (website)

The purpose of the preceding citation is two-fold. First, it provides a brief overview of the various types of hearing loss and associated causes. Second, it provides an indication of the medical approach to treatment of hearing loss – "treatment" is successful with the use of medicines, surgery, or technical devices. There is no mention of sign language intervention whatsoever.

By describing a deaf child's difference using medical and biological terminology and often only in ways that are intimidating to the hearing parents, the medical profession has pathologized deafness as a deviance (Lane, 1999). The

following typical doctor-parent consultation as described by Lane (1999) makes a powerful statement about the importance of informed decision-making:

> Much will be said about impairment of spoken language, little may be said about acquisition of ASL. Much will be said about hearing loss, nothing about gains in visual perception and thought....while pursuing the infirmity model, the experts commonly remain silent about the cultural model....The parents meanwhile are in crisis and unlikely to be critical of that view. If the professional person does describe the [D]eaf community, it may well be in terms that are so concise that the parents do not really grasp an alternative conception of their child's status and destiny. The professional expert and the parents generally share the same hearing culture; they tend to evaluate and label the deaf child from that perspective. (p. 24)

The labelling process has a profound initial effect on the parents and subsequently on the child across his or her lifespan. The deaf child endures a process of quantification based on the ability to hear or not hear and after lengthy testing is "branded" as having mild, moderate, severe, or profound hearing impairment (Lane, 1999). Lane (1999) maintains that the medicalization of the Deaf community has produced ongoing friction between Deaf people and hearing people who claim to serve them. "Deafness will be a prison as long as there are professionals, doctors, educators, counsellors, program administrators, who do not really understand Deafness, but think they do and think they know what is best for us. They are often our worst handicap" (Gannon, 1987, p.5). Lane (1999) summarizes the conflict as a battle "for the right to define a problem and to locate it within one social domain rather than another – to construe it as a problem of medicine, education, rehabilitation, religion, politics" (p. 25). A description of this struggle may facilitate an understanding of the current situation confronting parents of deaf children in the North.

**Pre-Contact: Deaf People and Signed Languages in North America**

In order to understand the current issues, an investigation into the history of the Deaf in North America is necessary as well as an understanding of the availability of resources about deafness in the North, the needs of hearing parents of deaf children, and the manner in which social support is obtained. Documentation about deaf people living in North America prior to 1817 is scarce (Valli and Ceil, 1995) and an in-depth scan of the literature failed to identify any record. The story of Laurent Clerc and Thomas Gallaudet, two educators who brought formal education to the Deaf in North America from France with the establishment of the first school for the Deaf in 1817, is a well-known piece of folklore in the North American Deaf community. It has been assumed that formal sign language instruction was introduced during the same period. This assumption is incorrect and has been clarified in recent literature. Until the late 1970s, it was thought that deaf people in North America did not have access to sign language and only began learning and using sign language at the first school for the Deaf in Hartford, Connecticut (Cokely & Baker, 1980). In fact, there is evidence of sign languages being used in North America prior to 1817 in written records as well as oral histories.

It is thought that Aboriginal peoples of the Plains perfected sign language and that it was a true language with all of the linguistic and grammatical nuances of a spoken language. Cody (1970) identified the Kiowas as having been and continuing to be the most proficient signers. Further research has substantiated this claim, with particular reference to Aboriginal people of the Plains who used an elaborate signed language. These First Nations people used a signed language for communication with

people of other Nations whose spoken language they could neither speak nor understand as well as for daily interaction among themselves (Umiker-Sebeok and Seboek, 1978). In essence, if one Nation does not understand the language of another Nation, there exists an inability to communicate, in essence, "deafness". According to Umiker-Sebeok and Sebeok (1978)) families and communities used signed language with such frequency that it became second nature and the entire community when speaking in the oral language, accompanied their words with signs to conveying their intended message. Beyond discussion of signed languages used for trading purposes and everyday discourse, no mention of Deaf Aboriginal people or discussion regarding the use of sign language for the benefit of the Deaf has been uncovered in the literature. People primarily used signed language when they traveled, traded, hunted, and exchanged information with one another (Fronal & Dubois, 1985). Cody (1970) noted that orators found this method of using sign language a useful attention attracter because listeners would be forced to pay strict attention in order to get the message. This method of adding signs or gestures is still used today in many hearing cultures as a support in the performance of storytellers to create a more dramatic story.

Although no mention of deaf Aboriginal peoples has been found in the historical literature, documentation exists regarding interactions between deaf people and Aboriginal people. While the signs were different and there was disagreement when the signs were first presented, understanding was established and mutual compromise was successful. In some cases dual signs for the same idea or object remained (Mallery, 1972). Often the sign alternatives from the deaf perspective proved to be more

strikingly appropriate, graceful, and convenient than the sign alternatives presented by Aboriginal peoples (Mallery, 1972). Mallery (1972) notes that the more comprehensive signs of the Deaf were more often adopted than the Aboriginal peoples' signs explaining that this would naturally be the case as Aboriginal people enhanced the spoken language in order to communicate an action or idea whereas the Deaf never based the sign on sound but simply translated ideas into signs and therefore produced a more comprehensive sign language.

**Historical Perspectives on American Sign Language**

Over 150 years ago, Thomas Gallaudet, one of the founding fathers of Deaf education in North America, was a strong supporter regarding the use of ASL. Gallaudet (1848 reproduced in 1997) remarked:

> I wish I had time to go, somewhat at length, into the genius of this natural language of signs; to compare it with merely oral language; and to show, as I think I could, its decided superiority over the latter, so far as respects its peculiar adaptation to the mind of childhood and early youth, when objects addressed to the senses, and especially to the sight, have such sway over this mind, - when the expressions of the human countenance, with the general air and manners, attitudes, and movements of the body, are so closely scrutinized by the young observer, while he receives, from these sources, some of the deepest and most lasting impressions that are ever made on his intellect and heart, - and when his first words, singly, or in short colloquial phrases, which he hears uttered, depends so much on the unfolding of this meaning by objects, or combination of objects and circumstances addressed solely to his eye. The natural language of signs is abundantly capable of either portraying or recalling these objects and circumstances. The life, picture-like delineation, pantomimic spirit, variety, and grace with which this may be done, with the transparent beaming forth of the soul of him who communicates, through, the eye, the countenance, the attitudes, movements, and gestures of the body, to the youthful mind that receives the communication, constitute a visual language which has a charm

> for such a mind, and a perspicuity, too, for such a purpose, that merely oral language does not possess. It is greatly to be regretted that much more of this visual language does not accompany the oral, in the domestic circle, and, indeed, in all our social intercourse. Our public speakers often show the want of it, in their unimpassioned looks, frigid, monotonous attitude, and quiescent limbs, even when they are uttering the most eloquent, and soul-stirring thoughts. Would they but look out and act out these thoughts, as well as speak them, how much greater power their eloquence would have. (p. 79)

Gallaudet eloquently elucidates the beauty of ASL and gives some insight into why the Deaf community treasures and protects its language. Nevertheless, there are those who would argue that ASL should be eradicated and replaced with one or another version of manually coded English. This debate is addressed in a later section.

**History of Manual Codes of English**

By the 1960s, a new philosophy, developed by hearing practitioners, for teaching deaf children emerged and began to sweep across the country. As was stated in a previous section, ASL was effectively eradicated as a language of instruction in schools for the Deaf and an oral (spoken English) approach, using speech-reading and residual hearing was used until the 1960s, at which time several educators investigated the possibility of developing what have become known as manual codes [of] English (Stedt & Moores, 1990). Unlike American Sign Language, these codes "follow English word order, and contain specific signs for bound morphemes to signify English verb tenses, adverbs, and function words. They were also designed so that they could be presented in coordination with spoken language" (Luetke-Stahlman & Milburn, 1996, p. 29).

**The Language Debate**

By the mid-1960s, ASL and other signed modes of communication began to resurface in residential schools for the Deaf, replacing the oral/aural approach to teaching deaf children. There are several modes of signed communication including Signed Exact English (SEE), Sign Supported English (SSE), Total Communication (TC), Manually Coded English (MCE), and Pidgin Signed English (PSE). All of the above noted methods of signed communication, excluding ASL, are based on the English language in terms of structure, syntax, and semantics. Proponents of each communication method argue that their method produces the "best results", that is, the deaf child is better equipped for integration into a hearing world within the context of English language usage. One of the first decisions parents are confronted with regarding their deaf child is choosing a language and mode of communication. "Everyone in the field of deaf education has very strong feelings about communication methods....[This leads to confusion and frustration] for some parents because the experts disagree on what is the best method for teaching a deaf ...child" (Frazier-Maiwald & Williams, 1999, p. 91). Descriptions of the various languages and modes of communication can be found in Appendix 1.

A contradiction surfaced as this study evolved regarding the notion that ASL is not necessarily the native language for 90 percent of deaf children because they are born into hearing families. However, this notion is refuted in the literature. Regardless of the hearing status of parents, ASL is referred to as the native language of deaf children (Mason & Ewoldt, 1996, Woodward, 1982). Deaf children acquire ASL "naturally through socialization, rather than through formal classroom lessons; hence, it is deemed

a natural and native language to them" (Mason & Ewoldt, 1996, p. 293). Skutnabb-Kangas (1984) had previously made a similar argument, stating that:

> The mother tongue definitions have to be rethought so as to allow for situations where parents and children may not have the same mother tongue, especially by origin, and for situations where the mother tongue may not be learned in infancy and not taught by the primary caretakers. (p. 143-144)

"Native language can be defined as the first language to which a child has complete access ….and [a] native language can be defined as the first language naturally acquired and used by the child, whether or not it is learned from the parents" (Mason & Ewoldt, 1996, p. 297). The language debate (ASL versus the oral/aural approach versus manual codes of English) has raged on for decades. As has been demonstrated, various methodological approaches to teaching deaf children have evolved over time. This brief description of the methodologies and the ongoing debate as to which method is most effective regarding the language of instruction for deaf children is essential for creating the setting in which this thesis is based; a case study of deafness in a Dene community. In addition to the discussions on language issues and the cultural identity of the Deaf community, a description of Aboriginal experiences within the dominant Euro-Canadian society is required in order to present the difficulties parents of deaf Aboriginal children have in dealing with life's challenges.

**The Residential School Experience**

Part of the colonization process inflicted on Aboriginal people by Euro-Canadians involved attempts to assimilate Aboriginal peoples. The most devastating impacts on the Aboriginal peoples of Canada occurred under the guise of education

within residential schools. The schools had a devastatingly negative impact on many Aboriginal people - their language, cultural identity, and community. As the Royal Commission on Aboriginal Peoples (1996) observed, residential schools have long been the means of attempts by government and church authorities to use education to control and assimilate Aboriginal people[12]. The condition of Aboriginal residential schools was investigated and documented by Dr. Peter Bryce in his book The Story of a National Crime: An Appeal for Justice to the Indians of Canada (cited in Waldram, Herring, and Young, 1995) and MacIvor (1995) states that the content and structure of western education has been irrefutably recognized as an attempt at genocide of Aboriginal peoples. Residential schools for Aboriginal children began closing their doors in the mid-1960s but the effects of the residential school experience are still being felt across Canada.

As previously described, the deaf experience at residential schools bears a remarkable resemblance to that of the Aboriginal residential school experience during the first half of the 20th century and allegations of abuse continue to surface[13]. However, in the last thirty years, the Deaf community has reclaimed the deaf residential school, identifying it as an essential component of the Deaf community, a cherished sanctuary to pass on the language and culture of the community. "The residential schools for deaf children provided a vital link in the transmission of [D]eaf culture and language, which

[12] See Chapter 1, Footnote 6 for an explanation of how attempts were made to assimilate Aboriginal peoples. The Euro-Canadian population wanted to subjugate and eventually annihilate Aboriginal peoples.

[13] Two schools for the Deaf, notably Jericho Hill School for the Deaf in British Columbia and the Newfoundland School for the Deaf, have been sued recently in class action suits regarding allegations of abuse.

is why the [D]eaf community finds it abhorrent the dismantling of the residential schools" (Lane, 1999, p. 21). Residential schools are highly valued in the Deaf community and residential school ties are seen as an important connection between members within the culture. When asked where they are from, Deaf people customarily respond with the

name of the residential school they attended. The residential school is viewed as an integral site of cultural and linguistic transmission for Deaf people, mainly for the reason that, as stated earlier, nine out of ten deaf children have hearing parents and only begin to learn their natural language and culture at residential schools.

Deaf identity among the Deaf community has great significance. "Deaf people seem to agree that a hearing person can never fully acquire that identity and become a full-fledged member of the deaf community" (Lane, 1999, p. 17). The Deaf community is heterogeneous in composition. Members of the Deaf community identify their primary cultural membership as Deaf and relegate their ethnicity to a secondary status in terms of cultural identity. These original cultural connections are not emphasized. The deaf identity "overshadows differences of age, class, sex, and ethnicity" (Lane, 1999, p. 17). Canadian provincial and territorial education policy reflects this assumption. Deaf Aboriginal children from the North are still sent to Deaf residential schools, which are housed in large, urban cities in southern Canada. These residential schools for the Deaf follow the mandated provincial curriculum but also include Deaf culture as part of the curriculum. The significant impact on Deaf Aboriginal children, their families, and the relationships that the child has with his or her original community

perpetuates the cultural genocide of Aboriginal peoples. The deaf residential school experience for deaf Aboriginal children may be akin to an "out-of-culture" adoption. This notion will be explored further in a later chapter.

**Providing a Context: Disabilities in the North**

Research literature on disabilities has gradually made its way into mainstream health-related literature. Disability groups across Canada have created awareness through the National Access Awareness Week and with strident lobbying of the federal government. In a recent Federal Task Force on Disability Issues (Government of Canada, 1996), task force members were:

> Acutely aware of the fact that the unmet necessities of life very often dictate where Canadians can live in their own country. No province or territory would willingly be seen as a place that is inhospitable to individuals with disabilities....Yet, this reality is a fact of daily life for many people with disabilities across Canada. (p. 16)

The services, education, and employment that individuals with disabilities need to assist with independent living may not exist in some regions (Government of Canada, 1996). Beyond this report, research literature on people living with disabilities in the North is scarce. "The focus on health [-related research] in the North has only begun to surface and not surprisingly, disability issues have yet to come to the fore" (Castleden, 2000, p.5). At the time of this study, the recently established NWT Council on Disabilities was conducting a needs assessment across the North in an attempt to determine the characteristic needs of the disabled population, which includes the deaf population. Prior to the NWT Council, no organized territorial body representing the disabled

residents of the NWT had been established. The results of that assessment were not available at the time this thesis was written.

**Contemporary Health and Education Services for Aboriginal People in the North**

According to Statistics Canada, the population in the NWT before the division of the Territory into Nunavut and the NWT was composed of 62% Aboriginal peoples and 38% non-Aboriginal peoples (Statistics Canada, 1996). Western heath and education services have become increasingly available to residents in the North with advancements in transportation and technology. Nursing stations and schools can be found in most communities. Medical professionals are available on a routine basis and nursing staff living in most communities are on call twenty-four hours a day. Communities have either a community-controlled school and board or regional school board, facility, and staff. Medical evacuation services are available across the northern territories and regularly scheduled air service is possible to Yellowknife, Iqaluit, and Inuvik from outlying areas. The closest urban centre for Lutsel K'e is Yellowknife and in recent years, Yellowknife has been able to offer a wider range of specialized medical services as more medical professionals take up residency in this metropolitan city. However, there are still many services, resources, organizations, and materials that are not available to northern residents.

**Hearing Loss in the Circumpolar North**

In the circumpolar regions, ear infections and hearing loss are common among children (Baxter, 1990; Bjerregaard and Young, 1998; Courtois, 1990; Crago &

Tremblay, 1990; DeCourtney, 1998; Dufour, 1990; Jette, 1998; Kramer & McCullough, 1998; Martin & Macdonald, 1998; Moore, 1990; Niclasen, 1998; Zurita, 1992). For example, Niclasen found that "ear infections cover 13 percent of all diagnoses, 20 percent of infections, and 84 percent of the disease. Twenty-eight percent of the ear disease were chronic otitis media[14] found in a total of 4 percent of children, evenly distributed over the preschool ages" (1998, p. 141) in Greenland. Niclasen (1998) goes on to say:

> Diseases of the ear are known to be very frequent in Greenland and other arctic areas, in earlier days mostly as chronic otitis.... Diagnosis of chronic otitis was often found as a secondary diagnosis, and the incidence in the population is probably underestimated in this investigation. (p. 145).

Bjerregaard and Young (1998) support Niclasen's findings indicating that hearing loss is reported by ten percent of the adult population in Greenland and otitis media in Alaskan Eskimo children remains high and it is still a major concern. Zurita (1992) also recognizes that chronic otitis media is highly prevalent among Eskimo children. Additionally, families of low socio-economic status, living in crowded conditions, having poor sanitation, and receiving no or inadequate medical care are also at risk of chronic otitis media (Zurita, 1992). In a survey conducted in Nunavik, that has been considered representative of the entire population of Nunavik, the most commonly reported health problem was hearing problems and more Inuit men than women of all

---

[14] Loury (2000) defines chronic otitis media and the risks associated with this condition:
Chronic otitis media is a term to describe persistent or chronic middle ear inflammation. Children with Downs Syndrome and those who are Native American seem to have a higher risk of this condition. With prompt treatment, there usually are no long-term effects, unless treatment fails. Untreated cases or treatment failure may result in: hearing loss; speech and learning delays secondary to hearing loss; damage to the bones that assist with hearing and some of the skull bones; damage to the nerves responsible for hearing, which can cause permanent, untreatable deafness; extension of the infection into the skull or even the brain, which can cause death in rare cases. The cost of not referring chronic otitis

ages were affected (Jette, 1998). "Although ear infections were often cited as explanations of hearing problems in Inuit children and adolescents, rarely was it suggested that the frequent and prolonged use of snowmobiles, all-terrain vehicles, motor boats, motorcycles, and firearms reduced the hearing ability of Inuit men" (Jette, 1998, p. 634). In a survey conducted in Alaska, respondents were provided with a list of health problems and asked to indicate those problems that family members had experienced. The item "ear infections/hearing loss" was ranked third highest on the list; thirty-six percent of the respondents indicated that this was a health problem in the family (DeCourtney, 1998, p. 660). Bjerregaard and Young, known across the circumpolar north for their health research note that:

> "A study of children born in 1973-74 showed that 41% of Inuit infants across the NWT had experienced at least two episodes of otitis media before their first birthday, and in northern Quebec there was evidence for current or old otitis in 78% of Inuit children and hearing loss in 23% (Spady, 1982, Julien *et al.* 1987). Other studies also found a high prevalence of otitis in the Inuit of Alaska, Canada, and Greenland and demonstrated its important role in contributing to hearing loss and impaired verbal development (Littauer & Elm 1964, Kaplan, Fleshman *et al.* 1973, Reed *et al.* 1967). (p.111)

Even though hearing loss is frequently undetected, it is a considerable health problem among northerners. "Although infectious otitis media is a disease that is universally common in children, there is a particularly high prevalence among Inuit children of the Canadian North" (Kramer & McCullough, 1998, p. 265). "Middle ear disease with related hearing loss continues as a significant burden for the children of the central Canadian Arctic" (Martin & Macdonald, 1998, p. 268). Health care practitioners are

---

media is recurrent infection with ever diminishing hearing. Further risks are meningitis, facial paralysis, brain abscess and deafness.

still being challenged in terms of achieving satisfactory criterion for managing ear disease (Martin & Macdonald, 1998).

**Role of Aboriginal Parents in Children's Education and Health**

A significant body of research has identified the importance of a positive relationship between parental involvement and student achievement (Friedel, 1999). Low parental involvement rates have been documented in Aboriginal communities and overwhelmingly negative statistics concerning Aboriginal education have been attributed to these rates (Friedel, 1999). However, consideration of the reasons for this trend has not been noted in the literature (Friedel, 1999). This failure to examine the underlying causes of low parental involvement has a way of perpetuating myths and misinformation regarding the trend, the implications of which have a significant impact on the overall health of Aboriginal communities across Canada.

It is widely accepted that Aboriginal parents who have attended residential schools as children are not likely to fully enter into school activities once they become parents themselves (Haig-Brown, 1988). As stated previously, the general experience of many Aboriginal people in residential schools has been negative. Physical, emotional, verbal, and sexual abuse occurred in many residential schools in epidemic proportions across Canada. Given that adults consciously and/or unconsciously reflect on and draw upon their lived experience as children when determining ways of parenting their own children, it is not surprising that Aboriginal parents are wary and distrustful regarding initiating or maintaining a relationship with the school. Those who operated residential

schools manipulated their responsibility in terms of educating and raising Aboriginal children. Government Indian Agents as well as residential school administrators would assure Aboriginal parents and families that the residential school was for the good of the children. Under this relenting pressure, brought to bear by officials, Aboriginal parents began to question their own parenting capabilities in terms of being able to raise their children (Friedel, 1999). Parents often had no means to travel to residential schools to visit their children and even if they were able to make the journey, they would often be turned away. Residential schools were basically closed to Aboriginal parents and existed in isolation from the community. (Friedel, 1999).

Today, we continue to see the same manner of isolation of children from parents regardless of the fact that most schools are located in communities. Although the last residential school closed more than twenty years ago, the majority of teachers are still non-Aboriginal and many of these teachers are not familiar with cross cultural ways of teaching and learning. In addition, many teachers and school administrators fail to build relationships with Aboriginal parents, community leaders, and administrators. Aboriginal teachers who are employed in the schools usually receive their teacher training in non-Aboriginal institutions and as a result, often reflect the cultural biases of the institutions in which they received their education.

Parents need to be informed about how school systems function in order to actively participate in a school. "In virtually all school situations, minority group parents do not have access to the cultural knowledge (i.e. power) that would allow them

to act in appropriate or positive ways. As a result, it can often appear as if they do not care" (Friedel, 1999, p. 141). Without access to information about the school, Aboriginal parents encounter obstacles in supporting their children's education. Friedel (1999) describes a role of advocacy arguing that parents must act as an "independent force that initiates, implements, and monitors basic changes in the school structure" (p. 140).

In its final report, the Royal Commission on Aboriginal Peoples (1996) described the importance of culture within Aboriginal education:

> Cultural approaches start from the belief that if youth are solidly grounded in their Aboriginal identity and cultural knowledge, they will have strong personal resources to develop intellectually, physically, emotionally and spiritually. The ability to implement culture-based curriculum goes hand in hand with the authority to control what happens in the school system. Cultural programs can be added to the school curriculum, or the whole curriculum can be developed around a cultural core. The most established cultural programming can be found in school[s] governed by Aboriginally controlled boards. (p. 478)

The low achievement rates of many Aboriginal people in Canada have significant consequences "in that education is viewed as a fundamental tool for achieving the goal of self-determination" (Royal Commission on Aboriginal Peoples, 1996 as cited in Friedel, 1999, p. 139).

Similar conclusions have been found in terms of parental involvement in the education of their deaf or disabled child(ren). Morton (2000) confirms that many parents have not had regular and productive contact with their children's schools. Teachers and administrators in schools habitually decided on a child's placement,

program, curriculum, and services without consulting parents. Parents are either informed that changes were being implemented or parents were not informed at all. The general professional assumption has been that the educational system was better equipped than parents to make decisions concerning their child's education (Morton, 2000). Morton's description of the power dynamics within special needs school systems is uncannily similar to those dynamics found in Aboriginal residential schools. In essence, the parents of deaf Aboriginal children are removed from the system. Moreover, geographical distance between parents and support systems has an impact on involvement in the decision-making process.

**Access to Support Networks for the Deaf in the North**

The audiology department at Stanton Yellowknife Hospital was formally opened in 1980. At that time, one audiologist served all ages groups in Yellowknife and the entire western Arctic population covering 500,000 square miles. The audiologist visited communities one to three times each year depending on the number of people in the community and their individual needs. The audiologist saw an average of 70 people during a three-day travel clinic (Moore, 1990).

Programs and services are extremely limited in the NWT. Although improvements to these programs and services have been made in principle, any real progress on the ground may be less visible. Moore (1990) discusses the delivery of audiology service in the NWT:

> Rehabilitation programs available to [deaf] patients are limited. There is no clear mandate for the provision of preschool

> rehabilitation services in the N.W.T.. The Department of Education developed a new Special Needs Education Program which began in 1986. Prior to this time, children [who were deaf] were educated in southern Canada in residential placements. Since the implementation of the Special Needs policy, children have remained in their home community for their education. Although the policy maintains the family structure, the Department of Education has not provided funds to hire trained professionals to support the regular classroom teacher and parents in the development of the child's educational plan. (p. 631)

Clearly there are children and parents who have not benefited from the Special Needs policy and without the additional financial support from the Department of Education, the likelihood that regular classroom teachers have the skills to manage an entire classroom that includes children with special needs or different language needs would be rare.

In the home, it is not uncommon for families to develop "home-made signs" in order to communicate with their deaf child. This is especially true for families living in remote or rural areas, as there is generally no immediate access to language models, services, or resources. These home signs are a combination of gesture, body language, and facial expression. Home signs are often the first means of communication between parents and their deaf child during the initial suspicion stage and after diagnosis. However, once formal education begins for the family and the deaf child, the family must unlearn their private mode of communication and learn another system. To start over is not easy and the home signs are of no use in the new signing environment at schools for the deaf. Deaf children and their families must become skilled at new behaviours and a completely new and unfamiliar language (Magnuson, 2000) as well as cultural materials, norms, and cognition.

Many families with deaf children relocate to large, urban centre in order to access resources, services, and support networks. This migration to urban centres is not a new phenomenon. During the past decade of involvement in the Deaf community, I have witnessed this movement, not just from North to South but also horizontally across provinces because residential school closures force deaf children and their families to relocate if they want the deaf child to remain in a school for the deaf. School closures or the threat of closure is a clear indication that the language and education debate is ongoing. Professionals outside the Deaf community argue that mainstream, integrated education using Signed Exact English (SEE) is the best practice for the education of the Deaf, whereas the Deaf community and its advocates argue the opposite, that a first (natural) language be developed and culture instilled before attempting second language (English) acquisition and that the best place for this language and cultural transmission occurs in a school for the deaf.

**Social Networks and Coping Among Parents with Deaf Children**

The need for social support is always present and is particularly essential when a challenging life event occurs. At these times, an individual's own beliefs and attitudes surface and there is a need to resolve and validate them (Hintermair, 2000). Not surprising, this self-examination of beliefs and attitudes as well as the ensuing need for social support occurs among hearing parents of deaf children. Discussion and clarification of Hintermair's (2000) use of the concepts of general social support versus recent social support in terms of how it applies to parents dealing with a critical life

event is relevant to this study's research question. General social support involves the entire support possible to an individual and is experienced through societal contacts developed over the course of a lifetime (Hintermair, 2000). Recent social support refers to the type of support that can actually be drawn from support resources when one is in faced with a stressful situation (Hintermair, 2000). Social relationships that seemed secure often become unstable among families with deaf children (Hintermair, 2000). Existing social relations may lack the ability to sufficiently cope with the kind of life changing event that deafness introduces into family relationships. In such cases, there is a gap between the support needed and the support given. In these instances, people may find it frightening or threatening to associate with an individual who is sick (Lehmann, Ellard, & Wortmann, 1986; Wortmann & Lehmann, 1985).

When confronted with the distress of others, one is reminiscent of one's own defencelessness (Hintermair, 2000). Furthermore, people in the general social support network often do not know how to deal with friends or family who are having difficulties or facing challenges (Hintermair, 2000). Even close friends and relatives tend to remove themselves from the situation because they are at a loss as to how to help or because they are apprehensive about doing something wrong (Wortmann & Lehmann, 1985). When this withdrawal occurs, artificial networks need to be established in order to increase recent social support and cope successfully with a particular life-changing event (Keupp & Rohrle, 1985 as cited in Hintermair, 2000). Clearly, critical life events have an enormous impact on the lives of the people immediately affected by the event. When one considers the impact on the parent when

she or he first becomes suspicious of a child having a hearing loss and then having this confirmed by a health care professional, ensuing distress is to be expected. How this stress is dealt with depends on the available social support.

**Familial Support Versus External Support**

Several studies are available that deal with how relationships within the family function and how family members [respond] when confronted with a child who is deaf[15]. Hintermair (2000) discusses contradictory results of various studies on how relationships function within and external to the immediate family. For instance, some similar studies[16] have found that family members tend to support each other when confronted with the disability or illness of one child. However, some studies[17] with opposite findings indicate that support from outside the family was sought in terms of coping with a disabled or deaf child. Despite these contradictory findings, it is clear that a number of general or familial support relationships are strong and therefore help parents of deaf children to cope (Hintermair, 2000). If this general or familial support network does not exist or disintegrates for whatever reason, the external social service network is essential (Hintermair, 2000). In these circumstances, the external network is generally considered more supportive than the family support.

---

[15] For further reading on relationships among families with deaf children see Hintermair, 2000; Magnuson, 2000; Morgan-Redshaw, Wilgosh, & Bibby, 1990; Meadow-Orlans, 1994 & 1995; Bodner-Johnson, 1986; Brand & Coetzer, 1994; Poon, 1998; Greenberg, 1983; Henggeler, Watson, Whelan, & Malone, 1990; Lederberg, 1993; and MacTurk, Meadow-Orlans, Sanford-Koester, & Spencer, 1993.

[16] For examples see Henggeler, Watson, Whelan, & Malone, 1990; Dyson, 1993; Bradley, Rock, Whiteside, Caldwell, & Brisby, 1991; Vanfossen, 1986.

[17] For examples see Magnuson, 2000; Meadow-Orlan, 1994 & 1995; Minnes, McShane, Forkes & Green, 1989; Segal, 1985.

The argument is made that parents with social support in general have more positive interactions with their deaf child and that receiving support as soon as possible after the diagnosis of the child's deafness is critical (Magnuson, 2000). Hintermair (2000) indicates that the importance of social support goes beyond the family, confirming that a broader amount of social support and information provided by friends, relatives, and experts will diminish the level of distress among parents with deaf children and that the level of support that families receive from their extended families, friends, and professionals clearly has a strong impact on the quality of parent-child relationships.

**Hearing Parents Supporting Hearing Parents**

In his study, Hintermair (2000) found that parents who have ongoing contact with other parents of deaf children show significant reduction of isolation, stronger emotional bonds with their child, increased acceptance of their child, and improved interaction. He also reports that parents who frequently meet with other parents of deaf children have a closer, more trusting relationship with their child. By sharing stories and personal experiences with other hearing parents of older deaf children, hearing parents with deaf infants gain a better understanding of the situation and often experience a change in attitude in terms of their view towards deafness. In general, giving and receiving support and assistance is helpful in terms of coping with the daily challenges of life.

The degree of a child's deafness may play a part in the degree of parental concern and stress. For those parents whose children are profoundly deaf, contact with other parents of deaf children is especially beneficial (Hintermair, 2000). Parents of profoundly deaf children are often extremely concerned with how they will be able to communicate with their child(ren) and worry about the future (Hintermair, 2000). In these instances, the opportunity to share with parents who are in a similar situation is greatly valued (Hintermair, 2000). Evidence of how parental contacts can alleviate stress has been repeatedly confirmed with large groups of parents although these assumptions do not necessarily reflect the personal experiences of particularly caring or insightful parents or professionals (Hintermair, 2000).

The literature clearly confirms the need for hearing parents to have contact with other hearing parents of deaf children. My personal experience in the Deaf community for the past ten years also confirms this finding. In three southern Canadian cities where I have been a part of the local Deaf community, organizations have been established to create networks between parents of deaf children. I have been a participant in conversations with hearing parents who articulate, first the relief of learning from and sharing with others and then the satisfaction of being able to interact with families in similar circumstances. Parents with older deaf children often pave the way for parents with newly diagnosed deaf infants in terms of sharing their experiences with obstacles, barriers, breakthroughs, and the accomplishments of their deaf children.

**Deaf Adult Role Models**

The Deaf community stresses the importance of having positive Deaf role models particularly for deaf children with hearing parents. Parents who have frequent contact with deaf adults show considerably reduced feelings of isolation and improved interaction with their own deaf child (Magnuson, 2000; Hintermair, 2000). According to Hintermair (2000) hearing parents who are able to relate to deaf adults find they have more energy to physically and emotionally meet the challenge of raising a deaf child, and are better able to develop strategies for coping with everyday life. They also seem to develop stronger, positive bonds with their own children. Deaf adults can usually be found to assist hearing parents with all aspects of having a deaf child. In southern Canadian cities, there are established networks that connect these deaf adults with hearing parents, through the same or similar organizations that now link hearing parents of deaf children with other hearing parents of deaf children.

Ongoing parental social support, particularly with hearing parents of deaf children and deaf adult role models, is essential in communities where deaf children live. Social support can be regarded as "a cornerstone of psychosocial intervention" (Hintermair, 2000, p. 41). Regardless of whether the deaf child is at a residential school for the deaf or in a mainstream educational institution, parental social support is critical to the lifelong relationship between parent and child. Herein lies the crux of the problem for northerners. While deaf adult role models and other hearing parents with deaf children are readily available in southern Canadian cities, families living in the North may not be afforded the opportunity to share their experiences, gain new insights, or

come to understand deafness as a cultural and linguistic identity. Lacking this support, the parents and family of a deaf child may find themselves isolated and alone.

**Extended Family Dynamics**

As with any event that forces people to cope with a series of atypical lifestyle challenges, being deaf or hard of hearing requires a great deal of learning. Initially the parents and family experience a steep learning curve regarding the pathological, philosophical, and cultural issues regarding deafness. Morton (2000) explains this assumption from a family systems theory framework, noting that family dynamics are profoundly impacted when a newborn enters the family. A child born with special needs intensifies the typical stresses on a family. A child with special needs (i.e. deaf or disabled) requires particular support and education from parents who more often than not also need training so as to provide suitable care for their child. Concurrently, family members experience significant emotional turbulence while learning to accept that their child is different (Morton, 2000). Morton (2000) argues that members of the extended family, particularly grandparents, are underutilized resources in terms of involvement with families having a deaf child. The argument for involving extended family in the lives of families with deaf children is addressed in a later chapter.

**Early Language Acquisition**

In addition to the feelings parents experience that are associated with suspecting their child is different, communication between hearing parents and their deaf child is difficult. As mentioned earlier, many parents create "home-made" signs to

communicate with their deaf child. Furthermore, education in a manual language begins only once deafness is detected. As a result, deaf children with hearing parents clearly start acquiring language from a disadvantaged position (Morton, 2000). Language development naturally begins at a very early age. Parents begin communicating using either spoken or signed language with their children almost immediately. Infants are initially only receiving communication but in a matter of months begin to express themselves through facial expression and then later babbling (in either spoken language or signed language). Deaf children who are not yet identified as deaf and who have hearing parents do not receive the natural language stimulation they require in the early stages of language development. Conventional methods of hearing testing also mean a delay in diagnosis. Conventional methods for hearing tests are not always accurate or adequate and prenatal or postnatal deafness is often not detected until a child exhibits different behaviour and lack of speech development makes it evident (Magnuson, 2000). Detection of severe to profound deafness in children occurs very late in all communities when these conventional hearing tests are used (Bamford & Davis, 1998). The only way to ensure early detection and an early start on language and cognitive development is universal neonatal hearing tests (Magnuson, 2000). In addition, studies indicate that the advantage of early intervention by conducting hearing tests on newborns overshadows the stress experienced by parents when they receive false positive test results (Magnuson & Hergils, 1999; Watkin, Baldwin, Dixon & Beckman, 1998).

Negative consequences regarding all aspects of a deaf child's psychological development and mental health occur when there is a delay in initiating effective and highly developed language at an early age (Magnuson, 2000). Deaf children of deaf parents who use ASL to communicate perform considerably better linguistically, socially, and academically than their deaf peers with hearing parents (Magnuson, 2000). There is evidence that hearing families with deaf children who have ongoing interaction with deaf adults and other deaf children as well as a shared language in the home also seem to have significantly higher abilities in language, social skills, and academic performance (Magnuson, 2000). Theses findings would indicate that deaf children who engaged early in active, meaningful, linguistic communication with their parents (deaf or hearing) are the most competent in their social, cognitive, and linguistic development. These deaf children gain information and knowledge through this communication. They also develop behavioural and cognitive strategies, an understanding of themselves and others, and a sense of identity (Magnuson, 2000).

The ideal scenario is that diagnosis of deafness occurs at a very early stage in the child's development, that the parents are deaf themselves or have frequent, ongoing contact with deaf adults, and that parents are already proficient in sign language. However, many hearing parents have no formal training in sign language let alone an understanding of the political issues involved with language and educational choices for their deaf child. Hearing parents and hearing people in general often do not feel comfortable using ASL, especially in public. Hearing parents have a tendency to use ASL only when communicating directly with their child, which leaves the child

uninformed while creating a barrier to the child's language learning and cognitive development (Vaccari & Marschark, 1997 as cited in Magnuson, 2000). Many hearing parents who begin to learn ASL and use ASL with their children often do not continue to develop proficiency in ASL despite their best intentions. Additionally, although hearing parents are able to communicate concrete subject matter, they are often limited in their ability to communicate abstract thought, a limitation that becomes even more evident as the deaf child develops and requires rationalization of more multifaceted social and emotional subjects (Vaccari & Marschark, 1997 as cited in Magnuson, 2000).

It is important to recognize that determining a child as deaf is the first critical event among many that occur and continue to occur throughout the lives of families with deaf children. In addition to facing a steep learning curve about what it means to have a deaf child, parents and siblings are also confronted with the enormous task of learning a new language. That families are willing to put in the time and energy required to acquire a second language indicates enormous dedication on their part. Magnuson's study (2000) shows the importance for hearing parents to begin communicating with their deaf child using sign language as early as possible regardless of their rudimentary ability and lack of fluency in ASL. The essential goal is to expose the deaf child to language thereby providing that child with the opportunity to develop at the same pace as hearing peers.

**Stress and Coping Among Minority Parents of Deaf Children**

There is extensive literature investigating the impact of a deaf child on families but limited research on the specific implications of a deaf child in a minority family (Mapp & Hudson, 1997). Most parents experience distress when confronted with a child who is different. But parents have also indicated that they began to think optimistically, concentrating on the positive support and approaches they may utilize in relating to their deaf child, accepting their child, and moving beyond grief to focus on action (Mapp & Hudson, 1997). Mapp and Hudson (1997) investigated the relationship between ethnicity and coping with a child's deafness. According to their findings, ethnicity may be an important factor in forecasting how parents select coping strategies. Mapp and Hudson (1997) have conducted studies with African-American parents and Hispanic parents in the United States and have found that their ethnic background had an impact on how they dealt with the stress of learning of their child's deafness. They note that historically, African-American people were forced into slavery, discriminated against, and suffered other forms of victimization. Hispanic people are currently experiencing hostility, prejudice, discrimination, cultural-linguistic barriers, and poverty. The ways in which African-American people and Hispanic people coped with their deaf children were dissimilar in that the latter were more likely to distance themselves, employ self-control, seek social support, and positive re-evaluation than the former (Mapp & Hudson, 1997). As mentioned previously, Aboriginal peoples in Canada have endured similar oppression, both historically and currently, by the dominant Euro-Canadian society. In this study, it is important to consider that oppression occurs and will undoubtedly have an impact not only on coping strategies

but also on the types of supports, services, and resources available to Aboriginal parents of deaf children, particularly in the geographically isolated northern regions of Canada.

**Conclusion**

In the preceding pages, I have provided an overview of the literature that shaped my views of deafness as a cultural identity and the experience hearing parents have when faced with a medical diagnosis of having a deaf child. I have outlined some of the historical and contemporary issues and debates regarding the language and culture of the Deaf and the issues confronting hearing parents of deaf children. I have discussed the experience held by many hearing parents of deaf children, paying particular attention to the significant decisions they have to make on behalf of their children. The basic contention is that deafness impacts the lives of the immediate family, extended family, and broader community. The following chapter will address the methodology and research methods I used to gather information from the collaborating community on this case study. The following chapter also provides a description of the setting where this community case study takes place.

## Chapter Three

## Methodology and Setting

### Introduction

The first half of this chapter defines and describes the community case study research methodology used in studying the experience of having a deaf child in the community of Ehchoosay. Definitions of case study research abound and are thus addressed in this chapter in terms of this study. The primary methods of data collection included interviewing, observation, informal and formal community meetings (collaboration), and reflection. A brief description of each method is described. Given that this thesis is based on a cross-cultural study, I have included a section on my role as a non-Aboriginal researcher in an Aboriginal community, sharing my personal concerns. As I have decided to include the embedded learning I experienced while conducting this study, it is important to attend to a discussion on my understanding of community-based collaborative research. Briefly, it is my assertion that there is a continuum of participation and action embedded within the term of collaboration. This concept will be discussed further.

The second half of this chapter focuses on the setting for the case study, including a historical, physical, and cultural description of the community and an introduction to the participants. In addition, I address issues of building good rapport, gaining informed consent, confidentiality, and defining limitations of the study.

**Defining Case Study Research**

In determining the use of case study research for this study, I considered the question I posed in the thesis. According to Sackett and Wennberg (1997 as cited in Bryar, 1999) the thesis question being asked determines the appropriate research methodology, strategy, and methods. The definition of case study research has long been debated because there is uncertainty as to whether it is a research design or a research method (Bryar, 1999). Although definitions vary, there are shared fundamental aspects (see Appendix 2). The general consensus throughout the research community appears to be that "case study is a research strategy or design which makes use of multiple methods of data collection, straddling and making use of methods from the qualitative and quantitative traditions as appropriate in relation to the questions being examined"(Bryar, 1999, p.64).

Case studies have traditionally fallen under the definition of qualitative research methodologies and are often used in social science research. However, as noted above, case studies are now being used in qualitative research, quantitative research, or both (Pegram, 1999; Bryar, 1999). Case studies serve as an inductive contribution to either expand on a common response or to record an uncommon incident (Abramson, 1992). Case study research is a single comprehensive investigation into a particular real phenomenon. The single subject can be defined as an individual, a group, an organization, a community, or a society (Meiher & Pugh, 1986; Stake, 1994). The holistic position that case study research adheres to allows for any of the above to be identified as a single subject (Yin, 1994). An important characteristic of case study

research is that the data collection allows for the use of multiple methods (Yin, 1994). By using multiple methods, researchers are able to create a vivid representation associated with the subject (Pegram, 1999). Yin (1994) defines case study research as being "an empirical inquiry that investigates a contemporary phenomenon within its real life context, especially when the boundaries between phenomenon and context are not clearly evident" (p. 13).

Various authors offer different approaches for classifying case studies. Case study research can describe, explore, or explain (Yin, 1994). Descriptive case studies describe a particular phenomenon; exploratory case studies debate the value of additional research and suggest a variety of arguments or assertions; explanatory case studies search for explanations regarding various features and statements stressed by descriptive research (Pegram, 1999). The size of the unit of analysis can be used to categorize case studies (Hakim1987). As noted previously, case studies may range in size from an individual person to an entire population. Finally, Stake (1994) provides classification founded on purpose be it intrinsic, instrumental, or collective. Intrinsic case studies increase a deeper awareness of a particular case for its own intrinsic value; instrumental case studies provide information relevant to the development of theory or to other comparable cases; collective case studies research several cases to provide more extensive information about related cases (Bryar, 1999). Additionally, Pegram (1999) argues that case study research provides a suitable foundation for further evaluative research because a situation needs to be explored prior to evaluation.

Furthermore, many of the lines between the various categories blur because researchers have several changing interests (Stake, 1994).

The term "situated response" has emerged in the literature regarding research with Aboriginal peoples. The description of this type of methodology appears to be analogous with case study research. Hermes (1998) describes how a "situated response" describes her "goal of exploring a problem that was relevant to the community, in a way that was responsive to that particular context" (p. 155). Hermes acknowledged that her methods were not clearly defined before starting and that even after her dissertation was written, the methods still did not fit a single category or formula. This account describes much of what I felt before, during, and after my time in Ehchoosay. Park (1997) makes reference to this approach by describing it as "a way of writing about social phenomena" (p. 40). In this thesis, I have described my involvement in the study, the perspectives of several family and community members about a particular social phenomena and a description of my experience as an external researcher in a Dene community.

Rather than basing the case study on one deaf individual's life experience, I chose to base the study on a community's experience with deafness. I drew on a number of individuals from the community with differing relational roles to the deaf youth (see Diagram 1, page 53). These individuals became the single unit of analysis. The selection of these participants was in keeping with Meiher & Pugh's (1986) classification of a single case. Rather than selecting one participant on which to focus

## Rippling During the Interview Process

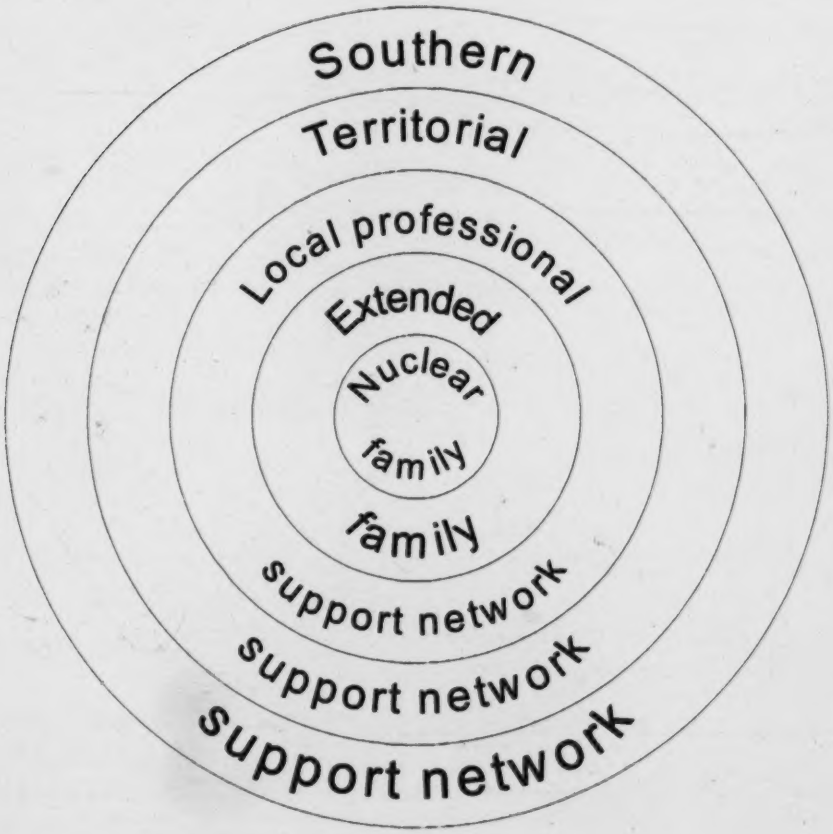



Diagram 1

the entire study, these community members provided a single unit of analysis that gave the research a holistic perspective. Given the pathological model versus cultural framework debate, I felt that it was critical to include the voices of those in the various relational roles in order to gain a deeper perspective on social support regardless of the final language, education, and cultural choices made by the parents of a deaf child. This approach is particularly appropriate when there is a unique or distinctive case (Yin, 1994). This study is both unique and distinctive in that despite broad database searches, next to no literature from a social science perspective was uncovered regarding the northern Aboriginal experience with deafness. This study validates for one community their experience in terms of having a deaf child in their community.

As previously stated, the data in this case study is unique. The data consists of one Dene community's situated response to a life-changing event; a deaf child in an isolated, northern, Aboriginal community and as such the community is unique. It is located on a lake in the Northwest Territories of Canada. This study concentrates on the community's experience with a deaf, signing child. The experience encountered in Ehchuse is not entirely dissimilar to that of other isolated, northern, Aboriginal communities confronted with childhood deafness nor is it far removed from the experiences of families who have a deaf child or deaf children in southern, densely populated Canadian cities. The case study of the Ehchuse experience with deafness provides insight into the community using a rational and lucid approach (Abramson, 1992). Ehchuse is a living, breathing, dynamic community and the voices that are

shared symbolize at least one part of the story that constitute the northern Aboriginal experience with deafness (Abramson, 1992).

**Validity of Case Study Research**

The issue with case studies is not whether they can be replicated in other settings and therefore generalizations can be made but rather what is reasonable in terms of generalizations (Platt, 1988). Validity in case study research is strengthened because the researcher is investigating a real situation (Pegram, 1999). Rather than statistical generalizations, analytical generalizations become the focus of the study (Pegram, 1999). Questions have surfaced regarding the use of case study research. For example, Abramson (1992) asks whether case study data augment theory development when alternative data exist and he speculates on the usefulness of case study research, particularly if it is not representative of a particular population. He also begs the question whether case study research may actually employ data that are burdened with measurement error. Runyan (1982) provides some rationale for case study data that include:

1. Providing "insight" into the person, clarifying the previously meaningless or incomprehensible, suggesting previously unseen connections;
2. Providing a feel for the person, conveying the experience of having known or met him or her;
3. Helping us to understand the inner or subjective world of the person, how they think about their own experience, situation, problems, life;
4. Deepening our sympathy or empathy for the subject;
5. Effectively portraying the social and historical world that the person is living in;
6. Illuminating the causes (and meanings) of relevant events, experiences, and conditions; and
7. Being vivid, evocative, emotionally compelling to read.

(p. 152 as cited in Abramson, 1992, p. 189)

Although he asks provocative questions, Abramson (1992) explains that the advantages listed above illustrate how case study data may be a powerful source of information regarding particular situations. Case study data also broadens the extent of knowledge about human circumstances (Pletsch, 1985 as cited in Abramson, 1992). Case studies are not usually undertaken in order to present facts, theories, or experiments but they do contribute in a considerable way to the body of knowledge, which have a significant impact on the formation of theories (Abramson, 1992). The issue of generalizability can be dealt with through triangulation in relation to methods and sources of data collection (Pegram, 1999). Additionally, validity can be enhanced with a theoretical framework, particularly if this framework is identified prior to entering the data collection phase (Pegram, 1999). The framework makes it possible to have a well thought-out method for rational inferences (Meiher & Pugh, 1986). The nature of case study research enables thorough exploration into a particular case. Probing permits a descriptive, exploratory, or explanatory representation to be developed (Pegram, 1999). Finally, case study research also acknowledges the researcher's involvement in the research process (Bryar, 1999). This aspect of case study research was particularly important to me as I approached my experience as a neophyte researcher from a humanistic[18] perspective.

[18] During my graduate studies in adult and higher education, I studied various philosophies towards teaching and learning, including the Rogerian (humanistic) perspective. Carl Rogers, was a central figure in the field of humanistic psychology for decades. I have adhered to Roger's interpretation of "a humanistic perspective" as a person-centred approach to life. To read more about this humanistic perspective, see Rogers, 1961, 1980.

**Methods**

My initial vision of this study was that it would be developed and carried out with input provided by pertinent stakeholders – in essence, a community-based or community-driven study. However, as the study progressed and I realized that I had not yet developed a comprehensive understanding of the difference between community-based and community-driven research nor did I have the time or the resources to undertake such a task. Instead, I engaged in qualitative case study research and employed a number of methods to collect data including personal in-depth interviews, observation, formal and informal community meetings, and critical reflection. In selecting a sample, I used what is known as opportunistic sampling. According to Patton (1990) opportunistic sampling is one method for identifying a sample:

> Fieldwork often involves on-the-spot decisions about sampling to take advantage of new opportunities during actual data collection. Unlike experimental designs, qualitative inquiry designs can include new sampling strategies to take advantage of unforeseen opportunities after fieldwork has begun. Being open to following wherever the data lead is a primary strength of qualitative strategies in research. This permits the sample to emerge during fieldwork. (p.179)

In doing so, I have brought together the different perspectives of people affected by deafness.

Interviewing is an attempt to understand the meaning of actions and events of another way of life from the insider's point of view, what Spradley (1979) calls cultural relativism. Rather than seeing myself as an expert, I considered myself as a learner in that I was learning from the people who agreed to participate in the study (Spradley, 1979). I was learning about what it has been like to have a deaf child in the community.

Beyond the direct research question, I was learning about myself as a researcher and I was learning about research in the cross cultural context. I was also learning about the difference between community-based and community-driven research. And I was learning about tanning hides, picnicking in the winter bush, ice fishing, caribou harvesting, and the importance of local community-driven research in Ehchuse.

The interview process also provides those interviewed with an opportunity to reflect on their experiences as Haig-Brown and Archibald (1996) note that participants "engage in dialectical interactions of action and reflection – praxis – in relation to both the research and their situations, thereby transforming those situations" (p. 246). My presence in Ehchuse addressing the question of supports and services for parents with deaf children may have prompted dialogue (with and without my being present) and reflection that community members may not have previously experienced. In this way, community members had an opportunity to change their perceptions towards deafness reshaping their paradigms and perhaps redefining their relationships within the community.

I had endeavoured to make the research process a collaborative one with the community. However, I began to realize that there were some aspects to true collaboration that were beyond my capacity as a neophyte researcher. "A collaborative or co-operative research process involves a researcher who is external to a group and members of a group collaborating to conduct research" (Castleden, 1992, p. 43). Castleden (1992) explains that this process requires "openness and trust as both external

researcher and community researchers come together to pursue common purposes in the midst of unforeseen occurrences and events (Reason, 1988; Torbert, 1981)" (p. 43). I did not have the time or financial resources available to provide potential community researchers with training in research techniques nor did I have the skills necessary to articulate or create the setting wherein true collaboration could occur. I did consider that each participant was sharing his or her personal knowledge, perspectives, and interests in the inquiry, and that this sharing had a direct influence on how I understood and analysed the data. I attended formal community meetings, meetings with the Chief and Council, and meetings with the Elders' Committee. I also had the opportunity of informal meetings with the Chief, one of the Council members, and the local Director of Health and Social Services.

I spent time in the community providing residents with an opportunity to get to know me as a person. This gave the community time to determine my suitability for pursuing my research question. I did not want to simply collect data and leave. I wanted to truly experience, if but for a short time, what life was like in Ehchuse. I could have been in and out of the community in less than a week in terms of data collection but I was genuinely interested in developing relationships based on mutual respect and reciprocity. I was deeply interested in pursuing the research question but I was not willing to prioritise this over becoming actively involved in the community and developing a personal sense of fellowship with participants. Part of my thesis describes my experiences living in Ehchuse.

The process of collaboration includes the process of reflection on the interpersonal relationships between the external researcher and the community. Castleden (1992) comments on "science as a reflective learning experience" (p. 44), reflecting the views of several others[19] who have written on the subject of collaboration. This particular aspect of the research process has been extremely significant in terms of my learning about how I might do things differently when I go about research in the future.

**Considerations**

I have asked myself how I, a non-Aboriginal, hearing person, could conduct a cross cultural inquiry in a Dene community regarding deafness. I did not want to follow in the footsteps of researchers who had gone before me into Aboriginal communities. Non-Aboriginal researchers have frequently exploited Aboriginal people (Inuit Tapirisat Canada, 1995; La Framboise & Plake, 1983; O'Neil, Reading, Bartlett, Young, & Kaufert, 1999, Smith, 1999). It is important for neophyte researchers like me to thoroughly grasp the many injustices that researchers have committed against Aboriginal people so that the same offences are not repeated. La Fromboise and Plake (1983) cite Trimble's seven-step process for obtaining participation in Aboriginal communities:

1. Initiate contact with members of the community to substantiate the need and value of the research.
2. Organize an advisory committee composed of community representatives.
3. With this committee assess the probable impact of the research process and its results on the community.

[19] For further reading see Castleden, 1992 who cites Lewin, 1946; Brown, 1983, 1985; Reason, 1988; Tanden, 1981, 1988.

4. Interpret and justify the research methodology.
5. Train indigenous interviewers and observers.
6. Prepare and develop culturally sensitive instruments.
7. Report the findings to members of the community in a style meaningful to them.

(Trimble, 1977 as cited on p. 50)

This process was particularly useful as a guide for my study. I made every attempt to adhere to each step in the process. However, as noted previously, time and financial constraints, both my own and the community's, forced me to make some amendments to this process.

As a non-Aboriginal person, I had concerns with respect to how I would conduct research in an Aboriginal community. I wanted to behave in a respectful and ethical mSandrar as I was well aware of the exploitation, misappropriation, and misinterpretation of knowledge by non-Aboriginal researchers in Aboriginal communities. I was anxious that I might not receive approval from the people that I wanted to work with on this project. In my initial contact, I felt quite unnatural and uncomfortable and it seemed like I was making a sales pitch. I felt incredibly awkward. I stumbled my way through my first conversation with the Chief and felt a sense of relief that he expressed interest in my topic. I realized at that time, that I needed to become a part of the community as much as possible and have people get to know me as a person before I took on the role of a researcher. I knew that I would feel more comfortable if I actually lived, worked, and participated in the community. I also considered the possibility that once I arrived in Ehchuse, I might not be able to engage anyone in the research and that perhaps my thesis would be based on personal reflection rather than the results of collaboration. Once I arrived, my method for data collection

was "guided more by cultural protocols" (Hermes, 1998, p. 161) than by academic traditions, authorities, experts, paradigms, or schools of thought (Sackett & Wennberg, 1997 as cited in Bryar, 1999). I embraced the role of researcher as analogous to that of a learner, apprentice, or neophyte not that of an expert.

Another matter of concern I had about conducting this research was that I was uncertain as to how to approach Elders in this particular community. According to Colorado (1988), there are cultural rules that do not permit Elders to share knowledge without being asked in a culturally appropriate way. Visiting Elders, which establishes an unspoken recognition of trust and promotes a genuine interest in the Elder, teaches the qualities necessary for conducting research, which includes enormous self-discipline, tolerance, and a readiness to communicate (Colorado, 1988). Although Colorado discusses cultural protocols in the generic sense, I felt that the visiting process she described was sound and certainly one that I endeavoured to employ during my time, not just with Elders, but with every individual with whom I interacted while I was in Ehchuse.

**Non-Aboriginal Researchers in Aboriginal Communities**

Readers may ask whether a white researcher should be carrying out research on a topic that involves Aboriginal people. Certainly the conduct of external research in many Aboriginal communities brings about negative feelings. "The word itself, 'research', is probably one of the dirtiest words in the indigenous world's vocabulary" (Smith, 1999, p.1). Research is not a neutral, academic endeavour, it is "an activity that

has something at stake and that occurs in a set of political and social conditions" (Smith, 1999, p. 5). Smith, (no date) addressed the complex question of external research in Aboriginal communities in a seminar at the First Nations House of Learning and Educational Studies at the University of British Columbia. She explained that while some make a case that a white researcher can be involved in Aboriginal research but not as the sole researcher, others maintain that no research is exclusively owned by any one particular group. Rigney (1997) adds to Smith's observations, indicating that "critical research by non-Aboriginal researchers should continue if it assists with the struggles Aboriginal people have for genuine self-determination" (p. 12). Smith (1999) cautions that:

> Many critiques of research have centred around the theory of knowledge known as empiricism and the scientific paradigm of positivism which is derived from empiricism. Positivism takes a position that applies views about how the natural world can be examined and understood to the social world of human beings and human societies. Understanding is viewed as being akin to measuring. As the ways we try to understand the world are reduced to issues of measurement, the focus of understanding becomes more concerned with procedural problems. The challenge then for understanding the social world becomes one developing operational definitions of phenomena which are reliable and valid....From an indigenous perspective, Western research is more than just research that is located in a positivist tradition. It is research which brings to bear, on any study of indigenous peoples, a cultural orientation, a set of values, a different conceptualization of such things as time, space and subjectivity, different and competing theories of knowledge, highly specialized forms of language, and structures of power. (p. 42)

With this positivist paradigm in mind, I have explored the acceptability of my involvement in this research study through informal discussions with Aboriginal and non-Aboriginal individuals, hearing and Deaf individuals, as well as through formal

dialogues within academe including participation in an Aboriginal Research Methodologies course. My concerns about undertaking this study have waxed and waned throughout the initial planning, during the data collection and analysis as well as during the writing stage.

I did not fully realize the extent to which power relations might play a role in my interactions with community members until I arrived in the community. The "researcher as learner" rather than the "researcher as expert" approach that I took in the community was one way that I attempted to balance the relationship that I had with community members. The interviewer, "with a focus on ethics, acknowledges power relations and attempts to deal with them" (Roman as cited in Haig-Brown & Archibald, 1996, p. 250). Haig-Brown discusses how her work exemplifies sharing power and demonstrates reciprocity between the researcher and the participants in that the research is useful. My approach to the interviews was based on the perspectives of Haig-Brown and Archibald (1996) who support the practice of maintaining an equal relationship with the participants, recognizing that participants' voices hold at least as much weight as does the voice of the researcher. The participants contribute ownership over their reality and lived experience as well as depth of understanding only one who has experienced a particular phenomenon could know, in this case, the research question. My hope is that this thesis proves useful for the individuals who participated in the study as well as the community of Ehchuse. The process of conducting the research for this thesis and the subsequent writing has been useful for me in terms of understanding my own limitations as an external researcher, understanding the difference between community-

based and community-driven research, and central to the research question, learning about the issues that surface for northern families and communities with deaf children.

**Permission to Conduct the Study**

This case study extends over a period of seven months, beginning in September 1999 and ending in March 2000. I initiated the inquiry at the University of Alberta in the form of a thesis proposal to the Department of Educational Policy Studies. The academy requires an ethics review of any proposed research being conducted under their jurisdiction. Once an ethics review committee gives approval (Appendix 3), the researcher may begin the research process. However, community collaboration in the North involves an entirely separate process. Because of an extremely poor historical reputation on the conduct of ethical research in the North, the Northwest Territories has established a policy requiring researchers to obtain licensure prior to conducing any scientific (social or physical) research in the territory. A detailed application is made to the Aurora Research Institute, the licensing organization for the NWT, and to any and all community organizations with which the research may have an impact (Appendix 4). For example, applicants must submit a letter of intent and copy of the research license application to the First Nations organizations, Metis organizations, Hunter and Trapper Associations, and Chiefs and Councils that will have direct or indirect association before, during or after the study. Additionally, the Association of Canadian Universities for Northern Studies (ACUNS) published a statement on the *Ethical Principles for the Conduct of Research in the North* (1982). This set of guidelines was produced to guide the conduct of research in the North. "They are … general principles that … encourage

research that is fair, honest, open, and where necessary, conducted with the consent and cooperation of whatever people or communities will be involved or affected …[by] the research" (ACUNS, 1982). At the time of my application, I wrote to several organizations outlining my proposed study, asking for permission to conduct the study. I also sought out those that were particularly interested in the study. Had I not received approval from Ehchuse (or from another community for that matter), I would not have gone to the community to conduct the research.

**The Setting**

During my stay in Ehchuse, I learned some of the history of the community through conversations with local residents. As a result, I have included a brief description of the community and the Dene people. However, this section is not a complete or thoroughly examined account (Abramson, 1992). It is included to provide a foundation and put the study into perspective (Abramson, 1992).

As noted in Chapter Two, families with deaf individuals tend to be found in large cities because they need to have access to professional and educational resources, to build networks, and to establish relationships with others families in similar circumstances. People in large cities have access to services and organizations that are familiar with the needs of the deaf population. For example, there are schools for the deaf, sign language interpreters, speech and language therapists, audiologists, social support services, hearing aid centres, resource centres, and community organizations for the deaf. I was interested in looking at the support services and resources available to

Aboriginal individuals who have deaf children or who are deaf themselves and living in northern Canada. Therefore, I began my initial investigation in Yellowknife, as it is the largest urban centre in the Northwest Territories.

Through a known contact in Yellowknife, I telephoned the Chief of Ehchuse, a community some distance from Yellowknife, to inquire about a family with a deaf son in Ehchuse. I explained my interest in pursuing research with the community regarding the supports and services available to the family and wider community. Thus began the process of gaining community support for the study and my application for a northern research license. I discussed my plan for the inquiry, which included interviewing members of the immediate family, the extended family, and the community in an attempt to gather a broad range of perspectives from those who were directly or indirectly affected by deafness.

According to conversations with local residents, the settlement was originally established elsewhere on the lake. At that time it was known for being situated close to a superb fishing site. A trading company established a northern store at another place on the lake as the water was deeper and the annual supply barge that provisioned the store was able to dock alongside the store, providing easier access. As a result of this arrangement, it was necessary for community residents to travel to the store to obtain commercial goods. Eventually, community residents migrated for trouble-free access to the store.

Ehchuse is, by conventional standards, a remote, isolated community. There are flights in and out of the community regularly though they are subject to weather conditions. Barge service is available once annually in the summer months. There is no road access. Additionally, many residents rely on personal means of transport including motorboats and skidoos (snow machines) to not only travel between neighbouring communities but also for hunting, fishing, and trapping. The community, as mentioned earlier, is located on a lake as are many communities in the Northwest Territories. The closest large urban centre is Yellowknife, the capital city of the Northwest Territories, which has a permanent population of approximately 17,000 people (there is a substantial transient population of 5,000). Yellowknife is located roughly 1,500 kilometres North of Edmonton, Alberta, which is the nearest large metropolitan area with over 800,000 inhabitants.

Ehchuse is home to approximately 300 residents. Aside from a very limited number of non-Aboriginal individuals, residents are members of the First Nation and are provided services by a tribal council and the community fall under a land claim area. An Aboriginal language is used in the community, as is English. A Chief and Council as well as an Elder's Committee govern the community[20].

[20] I have only a superficial understanding of the process of local governance in this community and as such will not attempt to elaborate further on this topic. However, I recall attending one Elders' Committee meeting wherein another researcher was asking for advice on the subject of employment. The Committee was asked to identify their preference for hiring a local community member to provide assistance on a research project. Once their preference was identified, the researcher announced that he would then take it to the Chief and Council for approval. One of the Elders piped up and said, with a glint in his eye, that there was no need to go to the Council as the Council would simply turn it back to the

In recent years, the trading company has been replaced by a local co-op. The Co-op has a small motel available for visitors to the community. The community operates a water treatment plant, sewage and refuse disposal service, water delivery service, heating oil delivery service, and hydroelectricity plant. Private individual sales of harvested goods (mainly caribou and fish), heating supplies (wood), and services (accommodation) are available in the community. There is also a Housing Authority and a Wildlife and Fisheries Office in the community. The local economy is largely based on hunting and fishing although arts and crafts, tourism, and sport fishing and hunting make significant contributions to the economy. A number of community members have administrative employment in the community and several residents are employed at a nearby mine on a rotational basis. Still others have left the community in search of wage-based employment, to attend postsecondary education institutions, or to access services and resources not available to them in the community.

Community children have attended the local school since it was established. Community youth must leave the community in order to complete grade eleven and twelve as the school currently extends only to grade ten. Aurora College, the NWT's community college, has a satellite campus in Ehchuse, which used to provide adult basic education and continuing education. At the time of this study, the facility had not been in operation for three years as there was no instructor available and no dedicated funding available from the College.

---

Elders' Committee for a final decision. There was much laughter and grinning around the table at that point in the meeting.

The community has an impressive 24-hour health centre. Nurses are rotated into the community from Yellowknife and Edmonton on a three-month basis. The centre also employs a local Community Health Representative who is often the first person to deal with community health concerns. A general practitioner and a dentist have regularly scheduled visits to the community. Medical emergencies are evacuated to the Stanton Hospital in Yellowknife. Individuals needing to seek medical attention from specialists fly out of the community and access these services either in Yellowknife or Edmonton. There is a new personal care home in Ehchuse, which allows elderly residents to remain in the community.

Ehchuse has a Social Services Department that provides services to the community. The Department employs a social worker, a community wellness officer, and an addictions counsellor. The Social Services Department also contracts short-term workshop facilitators who fly in and provide training on various topics of interest or relevance to community health and wellness. The Department also provides opportunities for individuals seeking assistance outside of the community. Ehchuse also has a very progressive environmental research office with several ongoing community-based and community-driven research projects. Several local residents are employed as community researchers and several external researchers are drawn to the community. The community is committed to exploring and researching issues relevant to the community's livelihood, health, and wellness and the external researchers are welcome as collaborators on these studies.

**The Participants**

I interviewed twelve community members and drew data from nine of these interviews based on their relationship with the deaf youth. The study became complicated in that by the time I had secured approval from the community to conduct the research, I discovered that the young deaf person whose presence in the community was to be the focus of the study was no longer living in the community because services, supports, and resources were lacking. In fact, he had left the community more than ten years prior. I only became aware of this fact after I had secured approval for the research from the university, the Aurora Research Institute, and the community. In addition, the professionals who had interacted with the youth when he was still in the community were no longer in the same professional positions. However, I saw the relevance of interviewing the current professionals in order to include a comparison of the services from one decade to the next. I wanted a cross section of participants that would include immediate family, extended family, and professional service providers, including individuals from health services and education.

I chose not to include an interview with the deaf youth, Arthur. This decision was based largely on the fact that as a researcher, I was a neophyte. An interview with Arthur would have required me to work in my second language, ASL and I did not feel confident in doing this as I had not used ASL for over a year during my time as a fulltime graduate student. Additionally, I determined that my research question was

more about parental needs in the North rather than the needs of deaf children, although the two issues are not mutually exclusive.

I interviewed Sandra, Arthur's mother, on two occasions. Arthur's father died in a tragic accident when Arthur was a young boy. Other family members including Arthur's paternal grandfather, Joe; one of Arthur's materal auties, Margaret and one of his paternal aunties, Carolin were interviewed. I also interviewed the local Community Health Representative, Tarah; the Community Wellness Director, George (who has a significant hearing loss); the school principal, Jennifer; the local Social Worker, Barb; and Beth, an Audiologist working in Yellowknife. I held interviews with local Elders who agreed to share their experiences living with or living with someone who had a hearing loss in the community. In addition to carrying out formal interviews, I engaged in numerous informal exchanges regarding the research question, including discussions with the Chief, one of the Council members, the local director of community-based research; and a friend from the North living in Yellowknife, who has been actively engaged in northern research issues for years and is an expert in participatory research methods.

**Developing Rapport**

Developing a relationship with community members was an important step in the research process. According to Spradley (1979) "interviewing involves two distinct but complementary processes: *developing rapport and eliciting information.* [Good] rapport encourages [participants] to talk about their culture. Eliciting information [in

turn] fosters the development of rapport" (p. 78, italics in original). This relationship-building process was critical in building trust between the community and myself. I also attempted to integrate myself into the community as much as possible before I began any interviewing, attending community events and meetings, volunteering for various fundraising activities, and visiting. My motives for doing this were based on the fact that I had a genuine interest in being a part of what was going on in the community and I was keen to learn as much as I could about the people and their community. I had some lived experience with First Nations communities in Manitoba and the time spent in those communities was an exciting time for me, meeting new people, learning new skills, and trying different activities. I was particularly excited about going to a First Nations community in the Northwest Territories because I had been born in the NWT and in a way I felt like I was making a journey back to a place that I belonged.

Perhaps the most significant way in which I developed a general sense of rapport with the community was through the hunting trip I went on. The day I arrived in Ehchuse, I headed down to the co-op to buy food for the weekend. A personal friend, had contacted a community member, George, about my arrival. She told me to get in touch with him as a way of introducing myself to the community. I bumped into George at the store and in the course of our conversation, I discovered that he was going hunting the following day. I asked if I might join them and he said I could if I could find proper winter clothing. I looked down at what I thought *was* proper winter clothing and said I would do my best to find the right gear. One of the local women I met on the plane said that she would try to find some gear for me. Luckily, I was able to borrow

some equipment and first thing in the morning I headed down to George's place. There were three hunters, another student who was doing research in the community, and myself going out on the land. George harnessed a sled to his skidoo, filled the sled with cushions and blankets, and tucked me in under a canvas tarp. We headed out across the frozen lake. After traveling for about an hour, we stopped by a small island. It was there that George pulled out a pouch of tobacco, inviting each of us to offer a prayer. I offered tobacco and said a prayer for the day.

I had never been hunting before and I was somewhat apprehensive about how I might react to killing an animal but as I sat in the sled, bouncing over the frozen lake, I began to realize and accept the difference between sport hunting and hunting for subsistence. We traveled for several hours, finally heading off the lake and into the bush. Our speed reduced visibly and I ventured a glance at our surroundings – it was breathtaking. We were surrounding by towering pines, brush, and clean, white snow. I marvelled at the natural environment around us. We turned a sharp corner and suddenly I felt the sled tipping. Seconds later, I was on the ground watching the skidoos swiftly growing smaller in the distance. Surely they realize that I am not in the sled I said to myself. But they continued to travel further and further away. In shock, I feebly shouted after them to no avail. My voice could not be heard above the din of the snow machines. Suddenly all was quiet around me. My heart began to beat faster, my palms were sweaty, and my knees were weak. I looked down and saw my expensive camera, a caribou hide, and a sleeping bag. I immediately began to wish my camera were a gun. After all, I was in bear, wolf, and killer caribou country! Did I mention my imagination

began to run wild? I had visions of caribou attacking me! After what seemed like hours, but was probably only fifteen minutes, I saw George off in the distance, on foot, walking towards me. With tremendous relief, I shouted and waved a greeting. As he approached, I saw he had a huge grin and was chuckling to himself. I too began to see the humour of the situation.

After a long day of searching for caribou we came upon a small herd and with little drama, the hunters harvested two caribou. The men quickly built a fire, using pine boughs for chairs, and we all gathered around as caribou ribs and kidneys began to cook. After our feast, we packed up the meat and headed for home. Twelve hours after we set out that morning, we arrived back at Ehchuse. I was cold but happy. Over the next several days, community members asked me about the hunting trip and I found myself telling this story repeatedly, each time with more laughter! It turned out to be an excellent preface to sharing my reason for coming to Ehchuse and introducing myself to the community.

By the time I conducted the first interview, I had already been on the caribou hunt with a group of hunters, I had attended a Chief and Council meeting to describe my study in person, I had attended an Elders Committee meeting to give details about my research plans, I had joined the local fundraising committee, I had learned how to fillet fish, I had joined the local community walking and tai-bo clubs, and I had joined the "sweat hogs" for weekly saunas at David's place. It was through this active involvement that I was able to determine who I wanted to interview for the study. I met

relatives of Arthur's family and individuals approached me, indicating an interest in discussing my research question.

**Informed Consent, Confidentiality, and Accuracy**

When I eventually began requesting formal interviews, I reiterated the purpose of the study and the question on which the inquiry was based. I explained that I might take notes and that I would use an audiotape during the interview. I also made it clear that each person's participation in the study was voluntary and that he or she could withdraw from the study at any time by simply telling me. Participants were informed that they could refuse to answer any questions and that we could stop the interview at any time. I tried to use non-academic language when describing the study and posed questions without using jargon.

I presented each participant with a consent form (Appendix 3). The consent form was written to conform to the academy's guidelines about confidentiality, opting out, and informed consent. However, there were a number of individuals who, rather than signing the form, gave verbal consent. When this occurred, I decided that verbal consent was acceptable and if there were any consequences at the university I would deal with it later as I was in the field, far removed from the university. I discussed this decision with my co-advisors and they agreed with my decision. I cautioned each participant that for the purposes of the academic community, anonymity could be assured by using pseudonyms but that the community of Ehchuse was small and even with pseudonyms anonymity would be difficult. Participants agreed to carry on with

their involvement, which testified to their level of commitment in seeing the study through to completion.

I have used verbatim dialogue in order to maintain accuracy. Three dots (...) or the term "(muffled)" is used when the tape recording did not come out clearly or when a portion of the comment is omitted for smoothness in reading. I also include questions in order to contextualize the interviewees' comments. Before defending the thesis at the university, I gave a copy of it to Sandra (hearing parent) and the Chief and Council of Ehchuse for review and comments. I have modified my thesis accordingly, correcting my interpretation of facts and events.

Before conducting formal interviews, I spent time visiting each participant. I used open-ended interviewing techniques that allow the interviewees to share their stories, memories, and their experiences without being unduly influenced or led by me. I mainly took on the role of listener during the interviews. However, I did incorporate analytical questions in the discussion and drew linkages between various ideas and concepts when appropriate, allowing the interviewee the opportunity to discuss the issues in whatever way he or she was inclined.

Developing rapport was the most critical stage of the research process. As an external researcher conducting cross cultural research in a small northern community, I needed to establish a significant level of trust if I was to elicit support and willingness to share information critical to the study. Part of the study included not only a search for

understanding the experiences had by those in a northern community exposed to deafness but also a personal learning process in terms of developing skills to conduct qualitative, collaborative, cross cultural research. This learning involved spending a significant amount of time learning culturally appropriate ways of establishing rapport and building new relationships. Given the amount of time I had in the community, I daresay that I only scratched the surface in terms of learning appropriate social behaviours and coming to understand the cultural boundaries.

**Limitations**

One of the most evident limitations of this study is that I am not Dene nor am I Deaf. However, from the outset I have been made it clear that this is a cross cultural study of those two (Dene and Deaf) cultures from a third (Euro-Canadian) culture. I realize that Western ideas have influenced the way research has been conducted in the past and Smith (1999) cautions, "Before assuming that such an attitude has long since disappeared, it is often worth reflecting on who would make such a claim, researchers or [Aboriginal] peoples?" (p. 56). It is with this awareness that I have attempted to conduct myself with honesty, integrity, and respect for the people who have made this study possible.

Another limitation was the amount of time I was able to spend in the community doing the data collection and analysis. Conducting research in the North is an extremely expensive venture, which may partially explain why there is a crisis in northern research. Given the recent report to NSERC and SSHRC from the Task Force on

Northern Research titled "From Crisis to Opportunity: Rebuilding Canada's Role in Northern Research", it is evident that scholars are urgently needed to contribute to the body of knowledge about the North and to become the next generation of Canadian northern experts (Task Force on Northern Research, 2000). As a university student, I was severely limited in terms of personal financial resources to fund the study. I was able to obtain a seed grant from the Northern Scientific Training Program provided by the Department of Indian Affairs and Northern Development to use towards transportation, accommodation, and groceries but the study would have been enhanced had I had the financial resources that would have enabled me to spend more time in the community engaging community members in a more collaborative process of data collection and analysis.

As the research is a case study and a situated response to a particular social phenomenon, the results are not necessarily generalizable. However, I would assert that there are certain characteristics and experiences of this community that do exist in other northern communities. This will be discussed further in the concluding chapter.

**Conclusion**

The methodology for this study uses a case study approach. Actual methods used included interviewing, observation, informal and formal community meetings (collaboration), and reflection. I took into consideration the community's situated response to deafness and that I was undertaking a cross cultural study as an external researcher. The study investigates multiple perspectives on deafness extending from

immediate family impacts to extended family participation and community and professional involvement. The following chapter contains the participants' perspectives regarding the research question.

## Chapter Four

## Northern Voices

### Introduction

This research was dependent on the context of a particular community in which I have gathered data. As indicated in the previous chapter, I have used a number of methods to collect this data including interviewing and observation. Individuals who were interviewed were selected through a continuous snowball sampling procedure (Babbie, 1992; Garvin, & Eyles, 2001; Patton, 1990) using the parents of a deaf child as a starting point and moving outward (see Diagram 1, Chapter 3 Page 51), therefore, the presentation of voices in this chapter has been arranged in a similar manner. In presenting the data, I have borrowed Bordowitz's (1988) video production model to produce different but related interview clips in presenting my findings. Hermes (1998) explains "Bordowitz's video production model [as] most compelling in that it brings together different perspectives, side by side, without resolving tensions or making sweeping generalizations" (p. 156). Similar to Hermes, I want to bring together different voices, by relating personal experiences and including quotes at length from interviews with community members in an attempt to detail personal stories and community struggles. My goal, like Hermes, is to do research that "serves a specific purpose or need of the community within which it is situated" (Hermes, 1998, p.158).

### Making Enquiries

I began in the fall of 1999, by contacting Frank, a family friend and native northern researcher with extensive contacts in communities in the western Arctic about my proposed research. I wanted to gauge his opinion regarding the feasibility of my

study in terms of community interest and relevance. Frank was extremely supportive of the research proposal and indicated that he thought the research was timely. He agreed to connect me with several individuals in order to identify a community willing to participate in the study. After several months of logistical planning and preparation, including obtaining approval from the Chief and Council of Ehchuse, where there was a family with a deaf child, and the Aurora Research Institute regarding my research license, I arrived in Yellowknife in January 2000. Frank and his wife, Judy, welcomed me and provided me with a place to stay while I was in Yellowknife. They also took time to discuss my proposed research and shared their views on research in the North, which included discussions on research methodologies and data collection methods as well as analysis and dissemination of findings. I began to consider Frank and Judy as the first of many informal advisors while I was in the North.

Once I arrived in Yellowknife, I discovered that the family with a deaf child from Ehchuse was no longer living in the community. At that point, I was not sure how to proceed. However, Frank contacted a colleague, Chris, who was familiar with issues regarding disabled persons across the NWT, and briefly described my research project to her. Chris agreed to meet with me that week to discuss my project and potential participants. When we met, I informed Chris that I was a certified ASL/English sign language interpreter. Immediately she indicated that I could find plenty of work as an interpreter in the North as there were presently no qualified interpreters. We discussed my research project for close to an hour and during that time we recognized the timeliness of my study as there was an NWT Council for Disabled Persons currently conducting a needs assessment across the NWT regarding disabled persons. Chris

suggested that I contact a Dene woman named Sandra who, as was quickly revealed, was from Ehchuse and had a deaf son. Chris and Sandra had had ongoing contact regarding Sandra's teenage son, Arthur, who was deaf. Chris contacted Sandra, explained the study and who I was, and asked Sandra for permission for me to contact her regarding the study. Sandra agreed and gave Chris a phone number at her place of employment, which Chris passed on to me. I called Sandra the next day and we spoke briefly as she was at work. During our telephone conversation, Sandra expressed enthusiasm for participating in the study. We arranged for a time to meet to discuss the research and her potential involvement in it. We decided to meet at her home the following week in order to spend some time getting to know each other. She sounded quite enthusiastic and I looked forward to meeting her.

When I arrived at Sandra's house, we introduced ourselves. Before I had a chance to go through the consent form, Sandra began telling her story. I did not take any notes or record our conversation during our first visit. At this stage we were building trust and rapport and I wanted her to feel comfortable. We talked for over an hour. During that time, Arthur, who happened to be in Yellowknife at the time, arrived at the house during this first meeting. His mother had explained to him that I would be there, the purpose of my research, and that she wanted him to meet me. Communicating in ASL, we greeted each other and I explained what I was doing in Yellowknife and why I had contacted his mother. He asked me a few questions regarding where I was from and where I had learned sign language. These types of questions are commonly asked when two signing individuals (deaf or hearing) first meet. I told him where I was born, where I grew up, where I learned ASL and who my first Deaf teacher was, where I took my

interpreter training program, where I had worked as an interpreter, provided names of Deaf people in my circle of friends, where I was living now and finally, I described what I was doing in Yellowknife and why I was meeting with Sandra. I asked him many similar questions as is customary in Deaf culture to establish shared connections. We chatted[1] for a short time and then he returned to his friends who were waiting outside.

As mentioned above, my first meeting with Sandra involved developing good rapport and establishing a sense of trust towards one another. I want to emphasize that I did not record our interview nor did I take notes, however, immediately after our interview I documented some pertinent statements that I distinctly recalled Sandra making during the course of our conversation:

- *"I am really excited about [the research project], but I am not showing it – it should have happened a long time ago."*
- *"I think this is really important. I want to help other families in the NWT."*
- *"I tried to get something going in Ehchuse but nothing permanent, even when there was someone [who knew sign language] they didn't have very good skills."*
- *"There is nothing in the community."*
- *"They (the professionals) 'over-institutionalized' him and they keep doing it to him even now."*

These statements along with the stories Sandra and others shared during the study were an indication to me that the research I was undertaking was significant not only to the community of Ehchuse but to the wider northern population, the Deaf community, professional healthcare workers and educators in terms of theory, policy, and practice

[1] The word "chatted" is an appropriate descriptor of our communication rather than using "signed". The Deaf community generally uses sound-based terms including "listen", "talk", and "say" during "conversation" (i.e. communication).

(Yin, 1994). Furthermore, there appears to be a complete lack of similar studies available in the literature, which suggests that this study may be unique.

I wanted to provide a holistic illustration of the experience of having a deaf child in a community from the perspective of hearing family and community members. I began by interviewing the person most intimately involved, Sandra, a single parent with one deaf son and three hearing children. I then expanded on her experience by interviewing members of her extended family as they were all involved to some degree with the situation. I also sought an understanding of each person's perspective regarding supports, services, and resources available in the community during the years Arthur lived in Ehchuse and how, if at all, these supports might have changed over the intervening years. I was seeking to understand what might be done differently and what recommendations might be made in the event that another deaf child were to live in the community. I was interested in the advice the family and community might give to parents who suspect that their child is deaf or to parents with a recently diagnosed deaf child. I was also looking at parental learning needs during the diagnosis stage. I was particularly interested in documenting a family's needs in terms of understanding how to deal with a deaf person in the family.

**A Mother's Reflections**

A second interview between Sandra and myself was held in Yellowknife approximately three weeks after our first interview. This interview was recorded and from the transcription a mother's story is told. I began by asking Sandra to share her recollections of how Arthur became deaf and how she came to realize his difference:

*When he was about nine weeks old, we found him with a red face on one side. I don't know still to this day whether he got mumps or....? The doctor, the nurse didn't think it was mumps. Just one whole side of his face was red. He was in a room where the windowsill was really low. It was summer and we had a fan there, one of those big square ones with air coming into the house. I saw there were tiny, tiny little bugs on the edge. You could see tiny little bugs – "no see ums", but we had a mosquito bar over him so I don't know how it could be that but we took him to the nursing station. It was my first time you know, my first child. He was really hot. His fever was really high. His father was scared too. So we just took him out right away to the nursing station and they cooled him down in a bath with cold water. I couldn't watch it. He was just screaming. They cooled him down a little bit and we took him home. They gave him a needle and he cooled down. After that it seems like it was a few months, at least a month after that he started having infections on that side of his face where he had the fever. He had to get medication, antibiotics. Then I had to follow up with doctors. Every time a doctor prescribed medication, I followed his orders but it just never went away. Then when he was about three months old, it just went from one side to the other side.*

To this day, Sandra is still not completely certain as to the cause of Arthur's deafness. It is clear that she still harbours frustration about her experience as a new parent, including the fears she felt, not knowing what was wrong with her baby. Sandra addresses the issue of additional stress placed on parents living in remote regions in the Northwest Territories. Not only is travel stressful for parents but as Sandra points out, being on a plane with an earache simply exacerbates the situation and the child's condition. The demands on parent(s) to care for a child with unique needs are enormous and there are often impacts on all facets of the adult's life, including changes to lifestyle, relationships, finances, interests, and learning. Sandra's experience is not dissimilar to other hearing parents with deaf children regardless of geographical location or cultural identity.

*The constant traveling back and forth on the plane too, from Ehchuse to Yellowknife when he was just a little one – I don't think that helped much either, especially with an earache. When the doctor came to the community all he did was give him antibiotics. So I traveled up here (Yellowknife) quite often. At the*

*time, I was in a training course for on the job training. There was just too much traveling back and forth. I just had to let [the job] go because of that.*

The difference between Sandra's experience and that of parents living closer to immediate medical care is clearly indicated in terms of critical intervention.

*Not too long ago, the doctor said when this thing started, if they had just taken him into the hospital in Yellowknife, pumped out his ears, kept him at the hospital and treated him instead of taking him back and forth it would have been prevented, his ears wouldn't have been damaged. It was really frustrating to hear something like that – like "should have" you know? He can't hear anything and I can't do anything. I can't go back.*

Sandra expressed frustration with the system that was supposed to be in place to help parents of children with unique needs, a frustration that had built up over the past eighteen years.

*I don't know what to do right now. Like I am so busy worrying about how to get Arthur some help....because he has been away from home since he was eight years old – no six years old – we sent him to Edmonton.*

Sandra conveyed how her suspicions that her son was developing a hearing loss progressed when he was still an infant. She continued to express her concerns with the local health professionals.

*How did I know he was Deaf? My sister-in-law came to visit us. She lived here (in Yellowknife) and came down for the summer to Ehchuse and spent a week. She noticed – and I had already noticed that he was only responding to sounds on his right side. So he still had his hearing. He hadn't lost it completely yet and he was three months old. That's when we found out and every time we would drop something on the floor he would just laugh and laugh. He would respond to it. Maybe he was happy because he could hear something I guess. When we would put him down for a nap, he would only sleep on the right side. He would only respond to things on the right. Right away, I noticed one side was clear and the other side was filled. And again, they just gave me antibiotics. I would give him that but I thought "this antibiotic isn't going to help" and "shouldn't we try something else?". But they never did.*

During the first six years, Sandra and her husband John, cared for their deaf son in Ehchuse. Early on, they began seeking professional support and services for their son

but the necessary supports and services were not available in Ehchuse. Sandra and John turned to their extended families for support in the decision-making process in terms of whether to send their son to the school for the Deaf in Edmonton, 1500 kilometers to the south. The professionals assigned to Arthur's case encouraged Sandra and John to send their son south. In the end, Sandra and John yielded to the professional opinion and tried the school in Edmonton for a year. Sandra went on to describe the feelings of anxiousness and fear they had during the time their son was away in Edmonton that year. Not surprising, Sandra and John reversed their decision and refused to send Arthur back to the School for the Deaf for another year. Instead, they lobbied for support and services for their son in the community. However, the problem faced by most northern communities is finding qualified professionals to provide the necessary support.

> *So after that, it was about, all that frustration, being at home and I don't know. I don't understand why they didn't take him or treat him. But now it is too late. He was six years old. We didn't know, like when he started school that there was no way to communicate with him. There was nothing available for him. He was seeing an audiologist and they suggested that we just try him out for a year in Alberta at the school for the Deaf. So we did. It was hard. It was really hard. His grandparents were saying no don't send him away. But, John and I, we made up our mind. We sent him to Edmonton and it was hard! It was just hard! When it was time for him to come back in the summer, we just didn't send him back. We just couldn't. While he was here in Ehchuse, we didn't just sit back and ignore the problem. We tried to do things, tried to set up things for him, schooling, however we could, eh? So they tried to set up something at Ehchuse school for him. But he went to five tutors because they were not skilled to work with people like that. They didn't know sign language so it was just impossible. The person teaching the class at the time – he was really willing to help. He was really trying hard to be supportive and get him some help. But it didn't work out.*

Sandra talked of the close relationship Arthur had with his father until John's tragic death. John's traditional livelihood, like many northerners, involved risk particularly when on the water or ice.

*His father passed away in '87. He had the whole summer with his dad. They went swimming and fishing – and the fall and the winter.*

In addition to their local struggle to gain access for their son, Sandra agreed to an interview with the Canadian Broadcasting Corporation (CBC) in an attempt to provide for her son. Even during this study, Sandra expressed a desire to help other families in similar situations:

*During all that struggle I went through an interview with CBC - anything to get noticed so that we could get something for people like him. And that was way back. Now he is like 18 (years old) and we are still struggling to get help. If anybody could imagine having gone through lots like this young man has – it took him how many years away from his home, because we couldn't get help here, from his own country – from his own community. And I am telling you this thing should not be ignored anymore. He may be the only one I know who is deaf but I am sure there are other parents who are going through what I am going through. Maybe there is somebody out there that has a little one that is going to be growing up and I have been waiting for so many years for something for my son -but nothing. Of course I want him to stay here in Yellowknife where we live now but there is nothing. I have met with the Department of Social Services but there is nothing set up at all. It is like every year (sigh), I don't know, year after year – I have been away from him. And the way I see it right now is that my son has suffered so much because of being away from home. He was institutionalized...he has a whole lot of anger inside him, frustration and anger from being away from home, and not being with his family. He's got a good memory. He remembers everybody from Ehchuse. If he sees somebody he will remember them and he'll be quite happy to see them. Every now and then he will ask how is he or how is she, you know?*

Grandparents play a significant role in the care and upbringing of children in Ehchuse. Sandra recalled how involved her parents and John's parents were with Arthur and how they were opposed to sending him to Edmonton because he would be so alone.

*His grandparents used to sing to him when he was just a little baby. You know how grandparents are with their little grandchildren. They used to sing in their (Dene) language and he used to pretend he was dancing. His grandparents have passed on but he still remembers his grandparents very well. His grandfather – he doesn't remember very well. John's father passed away when John was four years old. So John didn't remember him. Then John's mother met somebody from Ehchuse and they got married there. Arthur remembers both of his*

*grandfathers – and one is still alive. John's mum had said, "don't send him away he is too small - just wait until he is a little older." We said yes but we just had to do it. If I was by myself – I don't know. But because we both agreed upon it – we both decided to make this decision. We were talking to people from here (Yellowknife) – what do you think about sending your son away to a school, because he is 6 years old now, where there are more resources available. We had to sit down and talk with our parents – that's when they said no. My parents also said 'no don't send him away because he is still a baby'. It was going to be lonely and he might get sick of loneliness and die. Something might happen to him. If he gets too lonely, he might get sick. We tried to explain to them that we tried to get help for him but that there was nothing here for him. When we told our parents that – that we were just going to send him away but not for long, that we were just going to try it out – it was based on that. But sure enough, it was really hard. We were always worrying about him. We were always thinking.*

The residential school experience has had a profoundly negative impact on countless Aboriginal people. An enormous amount of trust is placed on those who claim to be able to provide the best environment for a child's learning. Appallingly, many children and their families are scathed by the experience. Parents feel a tremendous amount of guilt in the aftermath. Sadly, Sandra had little in the way of options for her son's education.

*There are so many things – so many things that have happened – if I could write some of the things that I was told by my son that happened to him while he was away in a whole different home. Some of the things he went through – he's been through so much. Like thinking about it now, I can understand how frustrated he is. I am here but John's not here with me anymore. If we had known then that he was being hurt at such a young age, we would have kept him here and really fought to get something done here for him. I don't know how that would have worked out but people who are skilled workers with the handicapped like my son – well sure we can find somebody but do they hang around – no. There are always people changing. They are always moving – coming and going. So we would say ok we will have this person for maybe like one year and then all of a sudden they would be leaving and we would have to find somebody else. It's not easy to find people to work with handicapped. I remember they set up a program to teach sign language to some of the school kids in Ehchuse. Three [adults] went from Ehchuse and myself to Edmonton for a sign language course. I think it was a one week or two week course but they didn't care so much. It was sad because I was really interested because that was my son. But, I wish they had a little bit more respect and sometimes they could not wait for the class to end or sometimes they*

*would not come. That's what has been going on. I think that is one of the reasons why they asked us to try Alberta. So, we did manage to get him back. We said no we are not sending him away again. His dad was the one who said no we are not going to send him away.*

Sandra reflected fondly about the time Arthur spent with his father before his death. She was initially concerned about Arthur's understanding of the accident but, using ASL, she was able to tell him what happened and check his understanding. After John's death, Sandra was left with four children, all under the age of eight, including one with unique language and learning needs. Living in an isolated community without the professional social supports she needed to cope with her husband' death and a deaf child as well as three other children forced Sandra to make a difficult decision; that is to send Arthur back to the School for the Deaf in Edmonton.

*He managed to spend that whole year with his dad. So that's why he has some really good memories of his dad. Then one day he (John) was gone. That's how it was for Arthur. He said, "where is dad?" I had to explain to him. So he understands that his dad was just gone. He was just gone all of a sudden. I couldn't do anything with him anymore like skidooing or going out for a walk or things like visiting grandparents. When it was explained to him everything that happened, he could picture it in his mind. I could tell he understood because he told it to me afterwards, "Ok, this is what happened to dad". He dwelled on it in the back of his mind, even though he was going to school. I sent him away after that. I couldn't handle it. I was left with four children, with a baby and two toddlers and Arthur. I didn't want to do it – I just had to do it. I didn't want to – it stung for me. I was living in a place where I had to cut wood myself and haul it all myself...I have to say that the number of times I had to go to the band office was really hard. Things didn't happen right away. I did sometimes get help from people but I would have to pay sometimes for wood too. Other times I would cut it and haul it into the porch.*

Carrying on with adult responsibilities, Sandra overcame major barriers (being a single parent, living in an isolated northern community) to pursue higher education and employment.

*When I sent him away, I moved right after that. A year after that, I moved here to Yellowknife. I also lived for a year in Fort Smith and was going to school. Then I moved back here and got set up here again and my kids were going to school. I got involved with Arctic College – academics – I completed that. I was really busy. I didn't do much work but a lot of schooling. Now I feel like I am kind of behind – I need to find a job that matches the skills I have. I feel like I am wasting my time here so I am going to move either to Edmonton or Calgary. When my father was alive, he took time to help looking after him. I had a lot of support from my parents, his grandparents, and my stepsister.*

The challenges and opportunities involved with raising children, both hearing and deaf, are immense. While raising four children, Sandra and John began to learn sign language and issues relating to deafness. At the same time, they continued to pursue avenues of access for their son in Ehchuse, Yellowknife, and Edmonton.

*We hardly ever let him go out of our sight. We had to be careful. We started to learn sign language and how to deal with the deaf. There were people here in Yellowknife. I don't know how many tests my son went through. It was frustrating for myself. Every time I brought him here (to Yellowknife) or his dad brought him to town – we took turns. We had to have a lot of patience and a lot of hope that something would happen that – but how many years now? What I don't believe is he is 18 years old now and they are still trying to find something for him in Yellowknife. Even when he was in Ehchuse, they were trying to find something for him here. Now he is in Alberta, he wants to be in Yellowknife and so they are still trying to find something here (in Yellowknife) for him. I have gone through lots but really he is the person who is carrying a whole bowl of frustration, anger, lack of communication, how he wants to connect. We learned about signing and how we could get help – how we could do it together. So John and I used to work on the sign language at home. That was frustrating too because he (Arthur) didn't always want to sit there – he was a little one. He knew that something was wrong with him too. We also had other kids at home to deal with so it was really hard to have structure at home for him.*

Many people are unaware and uninformed about deafness. Beyond the parental experience of shock, denial, anger, and eventual acceptance, extended family may experience significant emotional turbulence about a child who is different. Sandra and John did not have the opportunity to share their experiences as hearing parents of a deaf

child with other hearing parents of deaf children. No distance network across the Territory has been established to allow for the sharing of stories or personal experiences, which could alleviate some of the stresses involved in raising a deaf child. Deaf adult role models were not present in the community, which would have provided opportunities for Sandra and John, as well as their extended family and the community, to become familiar with the positive interaction and bonds that can be established between deaf and hearing residents.

> *In the community, his grandparents were there all right but it was also hard for the grandparents because they don't know how to deal with him. They were very protective of him. They just want to smother him with their love but they don't know how to deal with him you know? We didn't take any help from anybody except his grandparents. People used to call him retarded. People would come to help if we paid them. Other kids would pick on him or bother him. We couldn't really trust anybody – we were always really careful. I was always really protective of him.*

Family and social support are critical to a parent's well being. Both Sandra and Arthur have been through significant ordeals over the past eighteen years that have had dramatic impacts on their well being. The lack of support to meet their unique needs is evident.

> *The School for the Deaf is a big school. Some of the things that happened to Arthur there have made him become what he is today. He still has a lot of anger ... and oh God, there's so many things I could tell you about, I don't know where to start. In our first interview it was just an introduction ok, and now this is the second one and it is just like I have so much to tell you. I am just jumping from here to there. It's so hard for me to talk about it because it is so painful. I realize today and I see my son, he's been through so much and now he's in Edmonton right now. He was in a home there now. They set up a program for him and so they are working really closely with him and they are they're starting to realize that Arthur doesn't belong in a mental institution. They overreacted and that was wrong. So now they find out that he was diagnosed improperly. He's just normal. The program they have in Edmonton and in a way they deal with handicaps, they have a few people there from School for the Deaf. Arthur knows some of them. It's all just too mixed up, it's*

*so unorganized and I find it a little bit frustrating for myself and my son – they are not meeting our needs. I'm tired of this you know? I just want to be close to my family and nothing has happened yet. I want freedom and they give him a little bit of that but it is not normal. Right now everything is just so slow. Like Arthur has waited so long.....I don't want to wait any longer. Right now he is in Edmonton...I just want to drive there and pick him up and take him back here and work with him myself. That's what I told her - from social services. I'm willing to look after my son myself. I'm willing to work with my son right now. He wants to be here with his family. There's lots of things that you will learn ...it is probably going to help people.*

**Reflections of the Extended Family**

I wanted to provide an illustration of the experience of what it was like to have a deaf child in the community. I began to expand my research by interviewing the extended family based on the hypothesis that they may have had some degree of influence on the situation. I was particularly interested in exploring the extent to which the extended family had been involved with Sandra and John during the early stages of suspicion and diagnosis of their son's deafness. I was also interested in discovering how the family had come to accept and deal with a deaf person in the family.

**Auntie Carolin (Paternal Aunt)**

Carolin and I met on the day of my arrival in Ehchuse at the research centre adjacent to the band office. Carolin was employed at the centre as community researcher. We talked about her work as well as my study and, in the course of our conversation, I discovered that she was John's younger sister. I asked Carolin if I could have an interview with her at some point during my stay in Ehchuse and she agreed without hesitation. I spent a good deal of time at the research centre on a casual basis talking with local researchers, interpreters, and the elders' committee. The research

centre was a constant hub of activity and would often be filled with community residents
talking over coffee and pouring over maps that were being used for a local monitoring project. When I finally met with Carolin towards the end of my stay, we held the interview at her home over dinner.

Carolin began by sharing her feelings regarding the limited contact she has had with her deaf nephew. In general, members of the extended family often have limited contact with the deaf child because a communication barrier exists. The extent to which contact is possible is further diminished for those extended family members living far from urban centres where nuclear families often go to access the supports, services, and resources they need in order to provide for their deaf child. Subsequently, family ties are often severed because of the language and distance obstacles.

> *I feel sad about that there is no contact with him. It is not that I don't care you know. I do. It is probably more easy for him to come and visit us. Keep the family together. There is a gap. He was taken away from the family very young too. It would have been good if there was something available here but (muffled) .... there is no one else here that is deaf. So you would feel out of place in that way. But if we could (muffled) where he comes from his roots. To keep contact with his family, I think that is very important. I think that is lost eventually. And to learn some of his culture too. I think, not necessarily he doesn't have to live here you know cause he might feel out of place. Keep contact with the community.*

During my stay in Ehchuse, I shared with the community much about myself including the fact that I had been an ASL and English interpreter for many years. Several people recognized that it would have been ideal for Arthur to be in the community at the same time to take advantage of my skills so that meaningful dialogue could take place.

Carolin spoke of the value of having an interpreter in Ehchuse to assist with the communication concerning the family's need to heal over John's death.

> *While you are here too, the kid should come down and take advantage of your stay. Go to where his Dad went through the ice and stuff like that. For him to complete his I don't know, mission. I was thinking maybe something about him and I do myself to, I still think he is going to come back, cause I haven't seen him. I have to come to terms that he is not coming back. I am telling myself that now. I have to let him go. I can't hang on to him. It's been long enough. Even me I feel like that. He needs to come back to the roots if he wants to heal too. He probably understood, you know, things, I don't know. I know for me I feel frustrated with him, but then again that is how I perceive him, you know. He is not alone. You know they have their own uniqueness. They have their sign language. For me I would like to learn how to communicate with him. If he is deaf I don't know how he is going to learn this (Chipewyan) language. It would be kind of hard. But then you go out on the land and you learn how to make fire. You know doing cultural stuff. It would be really nice for him to come here and go camping. Because you know this is his Dad's and his parents', his family home. Like he hasn't been here for a while. I don't remember the last time he was here. It would be really good to have him here while you are here. I know probably it would make me feel good too because just to see him again, it would be emotional because there is a connection that is not there with me. I do feel bad for it. It's been 4 or 5 years since he's been here. It's longer, it's even longer."*

More than a decade had passed since Arthur had lived in the community. Carolin would have been a teenager at that time and so she had difficulty recalling specific memories. However, she has maintained a desire to renew her relationship with her deaf nephew regardless of the language barrier.

> *All I remember is my brother trying, Arthur's dad, was always trying to make me baby-sit. But there again, I feel bad about it that I am not able to say 'this is how you were and I used to keep you.' My mom when she was alive with us, we used to bring some food to my brother. So when my mom passed on, I used to do that too - bringing some food - that's what my mom did. But yeah, it's pretty sad. But I think just to reconnect with him that will bring me joy. It would be good to communicate with him and laugh with him and all that. I think we could manage. There might be a little frustration that we can't be able to talk out our feelings so, but just to have it in my presence, I'll be happy with that. It's better than nothing. But it would be good to have him. His mom did a lot of that (signing) and he did come to the house. I think we tried too a little bit.*

Carolin shared her feelings about having to make a choice between sending a child away to residential school or remaining in the community had there been the supports and resources in place to provide an education. Carolin also discussed the decision-making process that occurred among the family when Arthur was still a toddler in terms of language, communication, and education.

> *It would have been good I think to keep him with his family and to be able to have a class where he can teach other kids and when he gets older to have the option for him what he wants to do. For me I wouldn't want to send my child off. I know I'd get really heartbroken. It would have been good to keep him at home. I know that it was a tough decision to be at, if it ever happens, because there's no facilities here for that. I don't know if you have to have one teacher for one specific child, but there were cutbacks and all that. It would be very difficult. Even me, I don't know that much right now, so if we had more ... information so they could make a decision. That would be great because even me, I don't know that much, you know? I don't have the answers and they needed to know.*

Carolin indicated that she did not know a great deal about what it meant to be deaf in terms of language or cultural identity and she felt that this lack of knowledge created a gap in her understanding of why he was sent to the residential school. We discussed the historical context of residential schools for the Deaf and the similarities and differences in comparison to Aboriginal residential schools. Carolin asked if the Aboriginal students who attended the school stayed with Aboriginal or non-Aboriginal families. I explained that non-Aboriginal parents who have a deaf child at the school and also live in Edmonton often host another deaf child from the North who is Aboriginal. The deaf Aboriginal child is placed with the family because the parents use ASL in the home. Although ASL is the common language in the household cultural identity is different.

Carolin provided some suggestions and recommendations in terms of local supports and services in the event that another child is born deaf or becomes deaf in the community.

> *Try and put them here where they belong but it's up to the individuals. It would be good if they could offer something here for them, but if they don't, you've got to help their child too so they're not going to always take care of them. They're going to have to be independent too, so they have to send them out. It's something that they have to do. I wouldn't mind learning sign language - basic signs even, so I can learn about my nephew too - just where [he is] coming from. It's like I'm glad you came here and you're doing this because now I've got a little bit of understanding about where my nephew is coming from. But I'd really like to see him too. I am just happy that you're here and you met him. So when you go and see him you could give him a hug for me! Say that (the hug) is from your aunt. I'd just like to thank you for the opportunity to talk to us and it's great. There was a gap there and now I feel like there's something there for me and Arthur might visit now. I feel good about it.*

**Auntie Margaret (Maternal Aunt)**

I met Margaret during my first week in Ehchuse. She was one of two local Chipewyan/English interpreters and she was the interpreter for an elder's committee meeting that I attended. During the meeting I discussed my study and after the meeting, Margaret informed me that she was Sandra's sister. We chatted for a while and she invited me to stop by her place sometime to talk some more.

I visited Margaret on a number of occasions. On one occasion, I recall being called upstairs to her sewing room to sit down and have a visit. We talked about Chipewyan language use in the community and the importance of using it in the family as the primary language in order to develop fluency in children. I shared my experience of learning ASL and becoming active in the Deaf community as well as my experience living with a Chinese family for six months and learning functional Mandarin. We

talked about many things including all of the sewing she had done for her family. While she sewed, she explained the process of tanning hides. During one visit, Margaret informed me that she and her husband had talked about my study after my previous visit. She indicated that he was quite supportive of the study. She said that he felt that they needed a study like this so that the community was better able to respond in the event that another family had a deaf child.

When it came time for our formal interview at her house, Margaret evoked a memory of the experience her sister had during the early diagnosis stage:

> *I didn't know until after she went out with him to see the doctor and she was crying when she came in and I said 'what's wrong?' And she said 'my baby has no hearing, he can't hear with his ears.' There was something wrong with his ears. And before that happened that little child, he had a bad cold, a really, really bad cold. That's why she went to Yellowknife with him. I remember when he was just a little child, I used to hold him in my arms and I used to tickle his little foot and he would just laugh his heart out and he used to hear - I know that he used to hear. I know that he used to hear because when there would be a little noise, he would put his head up like that. You know? It was just that bad cold that he had, I think that's what blocked his ears or something and they couldn't unblock it or anything at all. So from then on, he would go to school here and they couldn't control him because he had no hearing. So my sister had to bring him to Yellowknife to a specialist doctor.*

Margaret made reference to changes in the degree of family support Sandra received after Arthur's father and grandparents passed away. She understood the demands placed on Sandra to seek out the services that would meet the educational needs of her son and she respected Sandra's decisions and has continued to maintain close contact with her sister.

> *At that time, his grandparents were still alive. His true grandparents and his dad was alive and after they were gone, there's nothing for her to stay here and she's concerned about her son and so she's trying to do something to get help.*

*The social worker helped the whole family out to Yellowknife and then from there and she has been there since then. And then he would go back and forth to Edmonton and to Yellowknife and he was in training - training for sign language while he was out going to school in Edmonton. And every three months his mother would go out to visit to see how he's improving and everything. The only way she can get help is for her to go to the south with him and that's what she did. If Arthur is in the right hands, in the right place to learn something, I'm pretty sure he'll make it. I felt sad when she left. The day that she was leaving she phoned and I talked with her for a long time and I think if this is going to accomplish something then go for it. We're really close. The family, we're really close. We're still like that.*

Living in an isolated northern community is difficult in many respects not just in terms of support and services for a parent with a child who has unique needs. Employment rates are often low and opportunities equivalent to level of skills are hard to come by. Margaret discussed her viewpoint as to why Sandra had also decided to leave the community.

*The reason why she doesn't want to come back is too many things going on around here. There's so much negativity and things like that that she doesn't want to get involved in. So that's why she took off from the town here and she figures that she'll....that she could manage her children somewhere else other than here, and there's nobody to come back home to. Like my mom and dad have passed away and there's, well she has brothers here, she has me here, but the job - she wants to get a job, a steady job and look forward to it every day but there's no way of finding any job within the community."*

Margaret recalled the supports and services that were available to the family when they were still living in the community. She made reference to a teacher who knew sign language that was in the community for a brief time:

*They had a teacher at that time who knew some sign language and he was teaching the kids sign language and somehow, someway, he came up and ordered a book for her (Sandra). It was like a big bible and it's got all sign languages on it and it gives you all the instructions on how to put your hands and everything on there. That's how she was teaching her son at that age - she started off signing sign language with him until he was about 4 or 5 years old. So it was good.*

Margaret's perspective on Arthur remaining in the South versus coming back to the North sheds an interesting light on the subject:

> *I'm glad in some ways that he went down to the south to experience the city life. He doesn't want to come back here because his friends and parents who he depended on are all gone. I haven't seen him. It's been about five or six years now.*

Margaret summarized her perception of her sister's experience while in Ehchuse:

> *She had to search around to get help. I knew that. Through the social worker and through the doctors that come here once a month to see how she could manage, to get more learning in the sign languages and everything, to have somebody instruct her to help them out or maybe to bring an instructor here, but it costs so damn much they couldn't afford it. So they had to send him out.*

**Joe (Paternal Step-Grandfather and Community Elder)**

I met Joe during my first week in Ehchuse. He was present at the first elders' committee meeting that I attended at which I had the opportunity to introduce myself to the committee, explain my reasons for coming to Ehchuse, and the purpose of my study. During that meeting, several members of the elders' committee had asked a number of questions about the study, shared their views on the topic, and expressed their concerns for community members who were experiencing hearing loss at later stages in life, including many of the elders who were around the table. After the meeting, while people were visiting over coffee and cookies, I began talking with Joe and at that time he told me that he was John's stepfather. This relationship to John meant that he is Arthur's step-grandfather and the only living grandparent in Arthur's extended family. I asked if he would be willing to share his recollections with me and he agreed to have an interview at his home.

Like most Dene men, Joe was highly self-sufficient and knowledgeable about the land by the time he was a young man. Knowledge about the way of the land is passed down from generation to generation. Joe has been hunting and trapping since he was eight or nine years old. There is a significant body of literature regarding young boys' rites of passage across many Aboriginal cultures. The Dene people of Ehchuse continue to pass along knowledge to the community youth. Inherent in this knowledge is the language and culture of the Dene. However, a Dene person raised away from the community lacks this knowledge. Joe described his life experience:

> *I used to go trapping with my old man. And my old man passed away when I was thirteen years old and so it was just me. I'd be in the bush alone, hunting, trapping. After thirteen years old I make my own house. I don't stay with nobody. My mum died when I was five years old. I remember it. And my old man raised me. And my old man passed away so I stayed alone. I didn't stay with anybody. And I get married, have kids, and my wife passed away. I could get married again but I don't feel like it. Not going to be like my wife. Going to be different. I used to have good wife. That's why I never get married.*

Joe talked about the Dene ways of life and how Arthur never had the opportunity to learn Dene ways. He compared Arthur's experience with that of another grandson.

> *He never learned it. Maybe six years old, they send him out. So he don't know how. One time he came here, he told me was going for a ride on the skidoo, he told me. He went to the skidoo and I told him no. I don't want to lend the skidoo I told him. You don't know how to drive. So, we went together. Yeah, I let him drive. I taught him right there. We went way up on the lake and then came back. He was really happy. Carolin's little boy can drive, he could drive alone. He is just a little boy.*

Joe also shared his experience with hearing loss, which helped to emphasize the seriousness of hearing loss among elders in the community.

> *I worked down at the fire house five years. That's why my ears are no good now and getting worse. If the TV or radio is on and somebody talks to me I can't hear it. I could hear it but I don't know what they say. That's why I go to Yellowknife to get an earphone. But it's still no good. So I need to get them to*

*send me another one. It's too weak. You can't hear even if you listen really hard. You just scream and I can't hear nothing. So I sent it back and they will send me another one. It will take three to four weeks before I get a new one.*

We talked for some time about his life experiences and in due course Joe began to share his recollections of Arthur. Like Sandra, Carolin, and Margaret, Joe mentioned that his grandson had been born hearing and had become deaf as an infant. Joe also talked about the lack of resources available in the community when his grandson was young:

*I think he was born normal but I am not sure. Because when he was a baby I liked to talk to him but he never said nothing. But now he can't hear nothing. You would think they could give him an earphone or something. It won't hurt him – try. Put an earphone in his ear. It couldn't hurt to give it a try. That would be better. If somebody wants to talk to him and don't know sign and get him to understand and maybe put an earphone in there and if somebody talked to him he heard it he would happy, yes.*

Joe talked about Chipewyan, his first language, and that there was a barrier to communicating with his grandson in Chipewyan. He was concerned that Arthur had not learning the first language of Dene people. Generally speaking, English, in its written form, is a second language for most members of the Deaf community and it is used to communicate with hearing people. However, this method of communication was not available to Joe and Arthur because they do not share a common form of language. Joe speaks Chipewyan and English. Arthur uses ASL and written English. Regardless, Joe was optimistic about how his deaf grandson could be integrated into the community.

*He don't understand Chip[ewyan]. He should have learned it. They sent him away and [Sandra] too can't do nothing because he don't understand - he can't hear nothing. Maybe he comes back to his mom, maybe he won't listen to his mom. Or he come here like maybe he won't listen to me too. I don't know how to sign. It's pretty hard. I don't know how to write too. If I know how to write it's*

*okay. I could write to him. He could read the thing. But he knows everybody. He could play with his buddies. It would be okay. He knows everybody.*

Joe acknowledged the fact that although many members of the community attempted to learn sign language, there was no one in the community who was proficient at using ASL to communicate. When asked how they communicated, Joe demonstrated some homemade signs that he had used in the past with Arthur. He went on to talk about what it was like when Arthur still lived in the community, how long it had been since he had seen his grandson, and his desire to communicate using sign language with his grandson.

*I used to keep him when he was small, a baby. And when his granny was still alive, I used to keep him. His mom and dad would go to Yellowknife for shopping or something. Maybe [it's been] four or five years now [since I saw him], I think so. Sometimes I miss him. I could learn it – sign, I could learn it. That would be good. You should teach it too to all the families. You should teach us. Then when he comes here he would be happy when we sign to him.*

Joe thought there should be opportunities for the community to learn ASL:

*They should do that – should have a teacher for that here. Our whole family could all learn something for when he come back. We don't know how [to sign].*

When asked if he thought it would be a good idea for not only the family but the whole community to learn ASL, Joe responded:

*They're going to have to!*

The underlying inference of his message was that the sign language would be beneficial to community members who are born deaf or lose their hearing at an early age as well as for the many elders and middle-age community members who are losing their hearing late in life. As the interview came to a close, Joe expressed a strong desire to see his grandson again:

*Before I die, I'd like to see my grandchild. The summer time coming here would be good. We could go for a picnic.*

After our interview, Joe showed me pictures of his family, including John, Arthur's father. I asked if it would be all right to visit again another time and he agreed. I called on Joe a number of times before I left the community. We played cards, drank coffee, talked and on my last visit, I brought Joe some homemade cookies as a way of saying thank you for the time we had together and in return Joe gave me a special gift, a reminder of him and of my time in Ehchuse. Joe also suggested that I take his picture to bring to Arthur. When I arrived back in Edmonton, I brought all of my pictures of the caribou hunt and community picnics as well as family photos to Arthur. When he saw the picture of his grandfather, he displayed joy and excitement, almost jumping out of his seat, as he signed, "I know him."

**The Professional Perspective**

Beyond the family, I endeavoured to provide multiple perspectives on supports, services, and resources that were available in the community during the period Arthur was living there and how, if at all, these services might have changed. I sought to understand what might be done differently and to identify recommendations that might now be made in the event that another deaf child were to live in the community. I also considered what parents, family, and community need to know during the diagnosis stage to make informed decisions regarding a deaf child.

**Beth: An Audiologist's Account**

One of the first interactions parents of deaf children have with the professional support network is with an audiologist who has been medically trained to diagnose hearing loss. I was concerned with exploring the current process parents undergo to gain access to information, resources, services, and support. I was also interested in the extent to which professional health and support workers in Yellowknife were involved with parents in outlying communities in the NWT.

The professional community population in the North is highly transient. The audiologist who had been in contact with Sandra when her son was first diagnosed as deaf almost two decades earlier was no longer in the NWT. Knowing this, I contacted the Stanton Medical Centre in Yellowknife to request an interview with one of their currently employed audiologists. I explained the purpose of the interview and provided a description of the study. Beth, one of two audiologists employed at the Centre, agreed to an interview. I sent her a copy of my thesis proposal and a consent form so that she would have a sense of the nature of the study before our interview.

I began our interview by asking Beth to describe the challenges of being an audiologist in the North. She identified two major challenges: working in isolation from colleagues and the difficulties associated with finding qualified professional staff willing to live and work in a region where the cost of living is extremely high and the work involves a great deal of travel.

*There's a lot of different challenges up here (in Yellowknife) than there were in Saskatchewan and mainly it's because you're so far removed from everyone and that's the challenge - you have to fly out to all of the communities and for kids who need new ear molds, you have to fly them to Yellowknife or you're doing it on your next travel plan to the community and things like that. We actually cover places like Fort Smith, Fort Providence, Fort Simpson, Inuvik, Cambridge Bay, Tuktoyuktuk, Holman, Pelly Bay, and Gjoa Haven. Thirty percent of our time is actually spent travelling and it's usually just the two of us, but right now it's just me, so we are getting people to come up from down south right now to cover the travel clinic because that just involves hearing tests and basic audiology things. Whereas here we do quite a bit more diagnostic testing, so my manager has allowed me to stay in Yellowknife so I get to do that – rather than travel. We are hoping to hire someone else but she can't start until June or July. For about a year, we've been looking for someone and they haven't been knocking down our door. But the money is not as good up here anymore. My friends make the same down south as I am up here and think of the cost of living up here, it's really not as worth it anymore. So if you're coming up for the experience and the way of life, I mean they aren't making as much but it is getting pretty close.*

I asked Beth to describe the prevalence of hearing loss and deafness in the Northwest Territories and to share her professional opinion as to why there is a higher incidence in the North. Beth cited a number of possible systemic problems associated with being Aboriginal living in the North, which have an impact on individual, family, and community health.

*Since I've been here, which is three and a half years, I've diagnosed two profoundly deaf children. I've had a couple of others that are in the more severe range, but as far as percentage wise, I don't even know that would be.... Basically the highest incidence is the middle ear problems, conductive hearing loss because there's a high Aboriginal population and they have a history of chronic middle ear problems and perforated ear drums and ear infections. So it is the highest incidence of that. There actually has been research and the research says it's [hearing loss] higher in the Native population. Why, I'm not sure. I mean I could speculate... there is a higher incidence of smoking up here in the native populations, I think nutrition and healthy food is expensive, so you do find that the money's not there in the communities, so poor nutrition. Education maybe as well isn't quite as high so they aren't aware if there is follow-up for the treatment that's to be required, and I know a lot of time we don't get the follow-up to the treatment. We might recommend treatment but they go in and [we] find out they have not been taking their ear drops and no they didn't finish that last round of antibiotics,*

*and you know if you are not taking your antibiotics that means of course a higher risk for (muffled) so the next time you get an ear infection, you may not be able to get rid of it as quickly. I have talked to the [ear, nose, and throat doctors], and that's kind of our speculation. I don't know if they've actually done studies, but the (muffled) tube in the Native population is maybe not as much at an angle...it may be anatomical as well. It's just like babies, and in babies the tube is more horizontal and then as they get older it starts to get in the vertical and if it stays more horizontal it is easier for bacteria to travel from the throat into the ear as well. So I don't know if that is a factor or not. Also I don't know whether or not, when they were in a traditional lifestyle, was it as much a problem as it is now? Now that white culture has come in and they're not...because it's like so expensive and you are finding a lot of people living in a very small confined space and the incidence of smoking is very high up here as well and studies have proven that because of the smoke, it will cause more hearing impairment - ear infections as well. Kids, second hand smokers, have a higher incidence of ear infections even though they are not smoking. It's hard to say if it's the lifestyle or is it anatomy or is it a combination of the two.*

Health care professionals in the field of otolaryngology (ear, nose, and throat specialists) have published research on differences in anatomy and Beth's remarks also support this observation. Beth elaborated further on the systemic problems with health care delivery in the North:

*When I go to the (community) clinic I am with the doctor so everybody comes to the clinic. I don't have a problem with no-shows and things like that. But all the other ones tend to have a real problem with people not showing up for their appointments or they'll go back six months later and nothing has been done and the recommendations haven't been followed through. So we're trying to revamp our service delivery because we want to show those communities who actually are doing follow up on recommendations for the community and build from there and hopefully other communities will see what's happening and go from there and hopefully those other communities will say 'well how come we're not getting this service?' Well you can if you follow up. So we're trying to improve the way we're providing services in the community. I mean it's a waste of our time, a waste of their time to go there and sit there for a day and read a book when nobody is showing up – when there's so many things you could be doing here.*

I asked Beth to share her perspective on the support services and resources regarding deafness that were available in Yellowknife. She confirmed my original

hypothesis that appropriate supports were unavailable in the isolated northern communities, inadequate in Yellowknife, and in order to gain access, individuals and their families would need to relocate to the south.

> *Well I find it very frustrating because I - as an audiologist - we really don't have the training...like we have the training to diagnose, like for profound hearing loss this is what we do and this is the hearing aide and the FM systems or and you have .... I think I'm good at saying these are your options – you can go with hearing aids, you can go sign language, and there is the cochlear implant, you know all about this stuff. But the problem with all of those up here is that, for me, I'm comfortable with diagnosing a hearing loss and say ok, let's try a hearing aide and see how those work. But, as far as the intense language that they need and things like that, I don't have education in that degree, I don't have...I have limited sign, I'm...and as you know, if you don't use it, you lose it! I can't see a kid every six months and be fluent in sign with them. So, no they don't have the support and services for speech and language stimulation that they need when they are in the communities. But I'd say Yellowknife is better because yeah, they get speech and [occupational therapy]. But all the kids that I have are in the community, so they're not getting that follow up, the native population is much more, what's the word I am looking for... not as (muffled), much more laid back and relaxed about it and I don't know if they don't realize the impact of early inventions or not, but I find that follow up is not always there with the recommendations. You can get home programming kinds of things, but they don't necessarily....and it's hard to get it. If you don't know yourself, how are you going to carry out the program right? And in a community there is the nurses but they don't have a clue about that either. And another problem is turn-over, every time you go to the nursing station there's a different nurse in there and you talk to them, explained how to change the ear molds and put the batteries in and then they're gone, right. And there's no one that's buying stuff here, like we did have a girl at the hospital, she was an interpreter out of Manitoba. She signed and so we did actually start up a sign language class for the parents and the kids, so we did have about six months where we brought them in every week from Fort Providence, and they did learn some sign that way. Plus our internet address and books have a lot of good signing so we did a lot of that kind of stuff. But as far as having the people that even know about deafness and things like that...and then they were asking about cochlear implants and stuff like that well an implant is about $30,000 and NWT Health Care, is like 'whoa! We can't pay that!' Plus they don't have the follow up - I don't have the follow up for cochlear implants here either. It would all happen down south and the follow up for the cochlear implant is intensive, I mean we'd have to be flying you down there from the community. I talked with one of the girls at the Glenrose [Hospital in Edmonton] and she said they had somebody in northern Alberta, something went wrong with the implants and they had to get him into Edmonton right away, they ended up having to take it out ....so I mean there's that whole issue. Like people ask about it and we tell them about it, but to me I don't*

*think so unless you're willing to move down south. And I say that, like the services aren't here, your best option is to go down south. But they don't want to leave their community either. So it gets...I find it very frustrating and it's like that one little girl in Fort Providence, she is so bright. And her parents actually kind of did surprise me, they've been very good and they've done a lot of research on their own - videotaping and things like that. She has an early intervention - like the HeadStart program and things like that, so I think other people have learned a bit of sign up there, but she is one those kids, she could just be a shining, signing star! If she went down south to get the services.*

I was interested in exploring the issue Beth raised regarding training for audiologists. The breadth and depth of academic training in terms of sign language, oral approaches, and cochlear implants varies across audiology training programs in North America. Therefore, the breadth and depth of information parents receive during the initial diagnosis phase also varies. Additionally, because the parents are experiencing a significant event in their life in terms of the diagnosis, often the information they receive is not absorbed immediately. The situation is exacerbated when there are limited and often transient resource personnel available to address all of the needs across the North.

*We were exposed - my class, we were exposed to it a little bit...but not every audiologist has the same background.... and I don't think at every university you'd have that program. I have this person here for like two hours and then they're going back to the community, I have to give them, that's the thing, you give them all the information at once and you know they're not going to remember it right, or if you just give them little bits and wait for it, but that's the hard thing too, you see them so little and you know they're not....I mean, even if you give them a little bit of information, that their kid has a hearing loss, but they don't hear what you say the first time anyway. I usually give them handouts, I have a whole filing cabinet full of handouts and stuff. And so I will try and keep it a little bit simple, but even then I still try, because I know, like that's the problem too - like do you give them the whole pile but that's so overwhelming they're not going to look at every single page. I kind of try to give them a few things every time they come. Another problem - you can give it to them but it's not guaranteed that they're going to read it. A lot of times they'll nod at you and you think they understand and then you go away and they don't have a clue or they're not going to follow up and literacy is an issue. And I did work with a little girl who had a hearing loss, and we got her and we actually worked together and did some auditory things with her. But now I just get a phone call*

*from (her community's nursing station) saying this hearing aide's not working and she hasn't been wearing them for the last couple of months and it's like what do you do? And I'm not a babysitter. I can't be on the phone telling these people all the time, they have to, and unfortunately it's the kids that are suffering. That's the frustrating thing. You try to follow up and say okay, like the idea is to try and see them before they start in the school year they go to the hearing aid clinic but I mean, we are so busy in this clinic, like one of us is usually always on the road or else on holidays or travelling. I do get quite stressed out and I have only been back at work for the last few months. I came back in January. But it's just like yeah, you're booked solid all day plus you're still getting phone calls from people in the community who are where ever and you have to find time for these phone.... I'm trying to do the bare minimal and trying to get by...it's frustrating. And you're one person who can only do so much. And they certainly don't want me to burn out. And that's a problem up here as well, especially for the nurses, they're not getting compensated anymore and the garbage they have to put up with in the community...I mean every three to six months they've got new nurses up there.*

The current process parents undergo to gain access to information, resources, services, and support is fairly constant once a child is assessed in Yellowknife. However, the extent to which the front line health care workers and nurses are informed about hearing loss plays a significant role in the turnaround rate for diagnosis. Travel time including severe weather that often disrupts travel schedules as well as insufficient available resource personnel slows down the treatment process in the North.

*The nurses are trained to do a general hearing test. But they have to come into Yellowknife for a more in-depth test. The nurse would actually set up the appointment with our Department and they would get scheduled right in. I know that one little girl that's in [a northern community], it was two years before she got diagnosed. But the parents had had concerns, they had gone to the nursing station and were told, 'oh she has an ear infection, we'll wait until the ear infection goes by.' So it ended up being two years before she came into Yellowknife to be seen. But yeah, depending on what kind of nurse you have, how educated they are and things like that and you can tell the incidence up here. That's another problem too is we have a kid in [a northern community] who ended up having a profound loss on one side and mild loss on the other side and we didn't catch him for a long time because we saw him, and we'd seen him quite a few times and he's always had an ear infection and he's been very inconsistent with his responses and things like that, so it's actually taken us awhile to catch him - but we finally got him without an ear infection and I'm like*

*'wait a second, this kid has a whopping hearing loss here'. And plus we were always seeing him in the community where you can't do the same kinds of things like that that you can do here, so yeah, sometimes we don't get, they don't get caught until later and we are actually in the process of setting up a screening process so at least the babies that are born at Stanton [Hospital in Yellowknife] automatically get a screening test before they leave. So and then there is supposed to be a high risk register in place, so that anyone that's high risk is automatically referred. We just got the equipment and I am supposed to be training on it but not until we find somebody else! It's really hard like training people how to do it and how to fill out the forms and telling babies' mums whether they passed or whatever. It's like all the paper work and all the calls will take a lot of time. So that will be good. It's not a universal screening program because it's not for all the babies that are born in the Territories but at least they can get quite a few and [Stanton Hospital] has the highest birth rate in all the hospitals.*

Beth elaborated further by comparing the delays in diagnosis and follow-up treatment and support between the North and the South:

*I think the actual diagnosis is later up here than down south, but I think as far as parents suspecting it, I think it is probably the same. In terms of diagnosis, there probably still is a delay. I think partly that is a big issue. The parents say they suspect and they're like 'oh, the audiologist will be here in a couple of months'. Well it's late! Then ok so we got them. But then we have to get ear molds and all that type of stuff and another month and then by the time you get that stuff and then we have to fly you down and another couple of weeks, so I mean it could still be another few months after they got diagnosed that we fit them, and then if there are problems with ear mold shrinkage after follow up or if they do decide to go with the signing route. Twenty years ago they didn't have any sort of services or everyone was being sent down south because (the audiologist) who was here before for ten years and he was quite stable and consistent, before him I'm not sure how, like I don't know how long they've actually had audiology services but until Jim came, like any special things always got sent down south. Most of those specialized tests would get sent down to Edmonton. You either wouldn't get it or else they would delay it as long as possible because it's expensive and you want to make sure that yeah, we need to send this person down south.*

Members of the medical profession, as stated in Chapter Two, often lack awareness about non-medical interventions for deaf children, particularly in terms of ASL, Deaf culture, and the Deaf community. As a result, parents who do not have exposure to all of the options for their deaf child are therefore hampered from making informed

decisions about their child. However, some members of the health field do have a superficial understanding and although they may not be fully familiar with all of the options, they do make attempts to share their knowledge with parents.

> *I don't know that much about the School for the Deaf. I don't know, like do they go and start at kindergarten there? I don't know if I knew if it was a residential school for the Deaf or not. I think I did. The one little boy here, I guess he was actually down there for a little while and it was awful - like the parents didn't want him down there, he didn't want to be down there, he had behaviour problems and things like that and then got back up here, and then I talked to them again and found out that he had worse hearing. They've never actually got appropriate (hearing) thresholds on him. The hearing aids he's had for the last seven years have not been strong enough for him, like the hearing was much worse than initially thought. So I put a new hearing aide on him and he was a lot better. But as far as the residential school, I know we did talk about the School for the Deaf - but the parents had no desire to learn from there and I don't know if they, I don't think, not at this point anyway I don't think they're willing to send their little three year old to a residential school. We actually did write a letter – well we had a few of the kids starting school, and we had another kid from the Eastern Arctic that moved here, he was deaf and his parents were doing sign, they had learned sign in the community and they knew ASL – that was pretty much all independent learning and so they would sign with him in the classroom and then they came to Yellowknife and put him in school and of course there is nobody that really signs here, right. But we did write a letter to the Department of Education and the Hard of Hearing Association and the parents all signed it and sent it to all the MLA's and like everybody to say the funding is not there for the hearing impaired. That was last year we did that.*

Beth showed me a copy of the letter she and others wrote to the Department of Education lobbying for funding for deaf children. It is clear that networking among parents and professionals has begun in Yellowknife in an effort to provide appropriate services for deaf children.

**Tarah: The Community Health Representative**

While I was in Ehchuse, I became as active as I could in community activities out of a strong desire to immerse myself in a northern lifestyle and learn from a unique

cross cultural experience. I volunteered on the community carnival fundraising committee, which involved regular meetings and fundraising activities including three community lunches of chili, stew, and fish chowder. I joined the TaiBo fitness class and the community's walking program. The community health representative, Tarah, led both the TaiBo class and the walking program. We began to spend a great deal of time together and we, along with Tarah's daughter, became a familiar sight walking the two kilometres to the airport and back in February and March. Our conversations ranged from my study on deafness to Dene ways of being, from what to take on a winter picnic to surfing on the Internet. Tarah and I brainstormed ideas for creating awareness about deafness and hearing loss locally and across the Territories. She was very enthusiastic about the study and about turning our ideas into action. At an early point in our growing friendship, I asked if she would be willing to have an interview in her capacity as the Community Health Representative (CHR) at the Community Health Centre. Tarah agreed to an interview without hesitation:

> *It is really important work that you are doing here. I am really glad to see somebody in the community that or somebody from the outside is really interested in the North. The North is so small; we don't really have a lot of resources. If a deaf person wants to move back here, there is no communication, no sign language, there's absolutely nothing for him, no services available and I am part of that professional team and I have absolutely nothing.*

As part of her responsibilities as a CHR, Tarah conducts hearing tests with community residents. The Centre did not have an abundance of resource material on hearing loss prevention, infant hearing loss, or deafness:

> *I do hearing tests here for my nurse. She looks at a patient and finds that he needs a hearing test and then she refers him to me. I do a hearing test. Mostly I do hearing tests from kindergarten to elders. If it is more severe, we usually*

*refer them to the ENT (Ear, Nose, and Throat) doctor in Yellowknife for the tests and from there, you know, the hospital. They give them a cleaning or they give them a hearing aid, it depends.*

Universal screening for infants in Ehchuse was not available at the time Arthur's diagnosis nor is it currently provided. However, doctors who come into the community may have some involvement with hearing tests.

*Not until kindergarten when they start school. It has to do with understanding. They have to understand what the test is for and so they would be referred to an ENT in Yellowknife. Once a month they have a doctor who comes to the community, and he has an appointment, he might tell the doctor I have a hearing problem. Then they will do a little test. If he knows what kind of problem he will right away refer them to Yellowknife for a check. We don't have the right tools here. If there is something I am kind of concerned about, I refer to the nurse. I think I would like to send them to Yellowknife. Other than that, if there is major ear drainage and other injuries, right away, automatically we send them to Yellowknife. For tests, further tests.*

The number of reported cases of people with some degree of hearing loss in the community requiring support in the recent past is significant. However, the majority of individuals reporting problems have not been parents with young children but adults in their middle to senior years.

*For the last three years, there is about ten of them have hearing aids. But they didn't know that they could have them. They would say that there was something wrong with their ears and they couldn't hear. So they would come in for a test and we would try that – they would tell the nurse. Again, we tell them if that is something that they are worried about to come in for a test and then we can get hearing aids. There has been a lot of them since I was CHR [three years]. Before that, there was no hearing aids here. I gave one this morning. The person came in and we fit it on and it was like 'oh, I can hear!' It isn't 100%, not like regular ears, or eyes, or whatever. You have to get used to it. Like any noise will be noticed. It will take one and a half to two months to get used to it. And you have to tell them that. Also it might be too tight or too sore and everything has to be adjusted. You have to tell them that. Every once in a while you see a patient and you have to tell them the same thing three or four times.*

In terms of Sandra and her experience in the community, Tarah was able to

share some of her memories. Tarah was not yet in her position as a CHR during the period that Sandra was in the community with Arthur.

> *I remember Arthur and some of the stories but that was before my time as a CHR. But, after becoming CHR I am aware of why he left and his mother was very, very sad. She couldn't cope with it anymore. There was no service available. She tried to send him to school but nobody could understand. There was no communication for that poor little boy. Even the mother had a hard time to communicate with her son because they didn't teach that little boy anything about the language and schooling. She was so upset. She tried everything and nothing – so she moved to Yellowknife. And then she enrolled her boy in that school in Edmonton. (muffled). And that's where he learned and so has she. But she had to do what he needed. But that was very hard to leave home at that age. I don't know how old he was – nine? Maybe eight or nine. Quite late, but he got some basic... and now he is a teenager, I can just imagine and feel how it feels like there is no communication with his peer group, his family, his parents, his sisters. It's like he is totally lost if he ever comes back. There is absolutely nothing to come back to. He has a grandfather he can't really communicate with. His grandfather doesn't know hand signs. Maybe someone could teach him how to say, 'how are you?' They probably shake hands or hug. It is still a meaningful bond that is there.*

Tarah discussed the options and the challenges involved with accessing supports and services in isolated communities like Ehchuse. She also spoke of the distress the community felt at not being able to provide the necessary services.

> *They would have to go to Yellowknife, and from there, there are lots of places she could look up in Yellowknife. There are lots of resource people in Yellowknife there. I am sure that is where she found out about the School for the Deaf. A lot of people are aware of the struggles that she had. There was nobody who could do anything here to enroll him or things like that. The health team here – it was very sad. We couldn't provide the service for him.*

Ehchuse was not new to the experience of having deaf or hard of hearing people in the community. However, the needs of each individual are generally very different and call for different resources.

*We have another elder, not an elder, but she is in her middle ages. She went to some training in Edmonton for a year or two. But she never used that sign. She was married and had kids. She could make a few sounds with her voice. Even that, the basic language, she could go around and find out, she was able to get around. She didn't have a lot of education but there was nothing here again. She raised her kids and moved on to Yellowknife. She went to some sort of education or something in Yellowknife for the Deaf. I don't know. She told me that she went to school in Edmonton. She had been there and learned to make signs. Even though we know this person, we didn't have the communication.*

Teachers in northern communities have very little in the way of additional human resources and the class sizes are often large. The local school is ill equipped to respond to the needs of deaf or hard of hearing children. Large classes also limit the time a teacher can devote to each individual and his or her needs.

*The teachers here are really overloaded with kids. They have very active kids. They don't have time for a special child to teach. Every child is special in the community in different ways. But that one especially [the one who is deaf], they don't have time for that.*

Tarah offered a number of suggestions for creating access in the community and the territory.

*I know there is lots and lots of hand signs. Maybe a videotape for the community, not just this community, but all small communities. I am sure they have some for the new generation to come, something like that for a resource in a place like this. That would be handy for the family, just a couple of signs, 'how are you', 'have a great day', 'I am going on the land with my friends.' Just very basic stuff. There should be somebody, a coordinator that goes around the territory to cover all the people with disabilities to inform them and inform the public – we are very close to these people. Some people are in their middle ages and some elders too. All these years they have difficulties – they still go out on the land. Never mind the cold or their aches. It's their lifestyle so they do it.*

Tarah shared her perspective regarding the pros and cons of sending a child to a residential school, where the child would be with his or her peers in terms of a common language and a new cultural identity versus staying in the community where they are with peers of the same original cultural identity.

*It is up to the parents to decide what the child needs, if the child needs some education in today's world with what's going on, with what's happening. They have a place to stay in Edmonton for so many months training and then once they have at least one year of training, then they could come back home. They could come back to the community and keep up with correspondence. That would be perfect, that way they could keep on going. But you would probably need a teacher, specially trained – again, you need another person like that plus a coordinator, a person to go around the territories and help with the correspondence and keep up the grades in order to graduate and go further on to be something. I wouldn't send my kids to a residential school like that because I have been to residential school myself and all those things – verbal abuse – all those things – no contact with family, no communication – it was very hard, very, very hard. You lose all those family bonds.*

Tarah created a wish list of things she would like to have in the community to deal with hearing loss among people of all ages in terms of support, services, and resources for the individual, the family, and the community. Her final comments provided insight into an ideal framework for the community:

*A videotape of sign language, very basic stuff like 'hi, how are you' things like that. Another video could be done in our native language so our elders can communicate with young people – this could be for relatives, like grandparents but even the general public and elders, like ones that want to communicate with young people. We don't have anything here. It is very sad. And a place where we can refer people, like if we had a coordinator say in Yellowknife. Someone we could ask what we could do, we could look up if a person needs a special place for education. There is no place where someone can go to school. There is nothing except home school and we are not trained to be teachers to teach our own kids. We have to be trained. We don't have the technology – nothing here. Even the computer for this person, this child, I know he learned how to read. A computer – to learn printing and learn to read. It has games. It would be a perfect communication for him. Also, a place like where they have a computer and he could spend hours with his mother and he could talk about what he did, and show them, show his grandfather, and they could share – maybe a library sort of thing they could use. You asked me about my wish. My wish would be to have all the disabled, the deaf, that they have a coordinator or a teacher that goes around to all the communities so that this child could continue to do their schoolwork. Plus communicate through computers in each community. That they have something to go to and use this computer to continue their education and communicate with resource people. Maybe with another deaf child, sort of thing, like pen pals and they could write to each other with email. Some of their friends in other communities - they could communicate that way. Something like that. I*

*would like to see that the child was able to graduate and go further on. He might get a job and do something that we could look on and say this child did it so if another child comes along we could do the same thing. I am happy to see all the disabled – they are starting to look up now – it is something new – the government has an agency that asked what is 'disabled'. Those surveys, the information they have gathered could make up a policy, something for the Territories. I would like to see this one learn his language so that he can even speak up at a general public meeting and say what he wants. It is a very important issue. Learn to read and write in Chipewyan. It's his culture, his language, his first language and it is a very important language that should be passed on.*

**Barb: A Social Work Perspective**

Barb, a member of the community, is the social worker for Ehchuse. I first met Barb at the airport as I prepared to board the bush plane to Ehchuse. After Frank introduced us, I shared my research objectives with Barb and there followed an animated discussion about my research question. She seemed incredibly supportive of the study and very welcoming about my presence in Ehchuse. It was only towards the end of my stay in Ehchuse that I decided to include an interview with Barb. I had originally wanted to meet with the Director of Health and Social Services and I tried to arrange a meeting on several different occasions but she was unavailable due to an enormous workload. Barb was also very busy but managed to find time to meet with me. Although Barb had little direct contact as a social worker with Sandra, she agreed to share her experiences with the family in terms of parenting support as well as insights about deafness in northern communities from a social work perspective.

*I have only had one occasion to be involved with Arthur in my role as a social worker quite a while ago. He had already been down south in a program down there. His mother was already living in Yellowknife. But they came here for a visit during Christmas. That was my only involvement with him... At that particular time, even I had a problem communicating with him. I don't have sign language. I didn't know how to communicate with him. That was the one time that I had been involved with him as a social worker... But I found that I*

*couldn't communicate with him. I didn't know him. He didn't know me. It was difficult for him because he didn't know me. But in the past, before I was working as a social worker, I knew him. I remember the family living here. I knew about his condition. I knew that he was deaf. It was very difficult to communicate with him. I didn't know sign language. I didn't have too much contact with him then. I think services, when we talk about services, to people in this community – we don't have any. We don't have any services. I am not sure about other people in the community, whether they have taken any sign language. I haven't heard anyhow. Probably none. I think people do a lot of pointing. I know I did when I was trying to communicate when he was here.*

Barb explained the current process that would be taken if there was another deaf child in the community.

*If we had a child here now, we would have to take it to the (school) board and we would have to advocate and lobby for him. They are the people we would have to try and get the funding from for the teachers and the resources. But did they provide a special needs teacher? I don't know. We have one in the community now (not a teacher for the deaf). We would have to lobby. We would have to go to the MLA and the Department of Education to lobby for a teacher. That's what we had to do for our special needs teacher and for our school counsellor position. We have kids with a lot of special needs however the regional board funds us on a per capita basis. That is, they fund us for the amount of kids we have here, not on an individual needs basis. That is really posing a problem. It is not appropriate for our community or our kids. The kids aren't able to get the proper education that they need.*

Barb shared her perspective, as a social worker, about the implications of sending a child out of the community to attend school in a large southern city such as Edmonton.

*I think maybe not that extreme as to go south [to Edmonton] (emphatic tone of voice) [but] out of the community, to a larger place, like for example, Yellowknife. I think that probably would not have had such a major or big impact on his family. We don't have the resources here. I know other people too, they need resources that we don't have here. They will relocate to Yellowknife temporarily to get it and then come back here. For example, with Arthur's family if they had the resources in Yellowknife that would have been much better than to have to relocate outside the Territories. I think at some point too his mother was down there. The family was down there with him but they ended up coming back up here.*

**Jennifer: Perspective from the Education Administration**

Jennifer, the current Ehchuse school principal, had been in the North on and off since 1973. She has worked with Aboriginal and First Nations people most of her life and with special needs children during her time in Ehchuse. I met Jennifer shortly after my arrival in the community. She generously gave me full access to the school's resources and willingly agreed to be interviewed.

Jennifer began by sharing a story regarding a particular family that she was aware of with a young deaf child in another northern community:

> *That child is profoundly deaf and no surgery or hearing aid is going to help her. [The parents] have had to learn sign language and how does she cope in school? Fortunately there is a teacher there with level 7 signing at the school where she is. The parents have been really supportive in going out to school and I think the Association for the Deaf have taught the dad to sign. So the parents are playing games with the child to broaden the sensory end of her development and eye-hand coordination. So that even though she is not a hearing child, she will not be impaired in other areas. Her development will be more rounded perhaps in comparison with other children who have all of their faculties because she is getting early childhood stimulus in case there are other neurological damages that are not immediately apparent. Once the deafness was clear and known then they said 'let's do an early intervention program so that the child is really well stimulated visually and more acutely aware than other children who are sort of quote normal'.*

Speaking specifically about Ehchuse, Jennifer was aware of children with speech problems. She speculated that alcoholism might be linked to deafness. I mentioned that I wasn't aware of a link between alcohol use and deafness.

> *Some of our students who are having speech problems may also have hearing problems. So I am not linking that to alcoholism directly but if it has been a confirmed link in other communities that could be a possible link in the North. I think they've had those hearing tests so it might indicate that there is a slight hearing loss. It seems to me if a child isn't speaking properly by the age of three and there doesn't seem to be any other developmental delays then it would point to a hearing loss as sort of a clear cut cause for not being able to reproduce sounds that are being heard. Maybe I am out of line with this ... maybe there*

*were other things going on for the fetus. It would be interesting to see if there were other studies because if that were so, with the amount of FAS and FAE in our children, perhaps there are other children who are also having hearing problems that aren't really evident or not as bad. But maybe that would be a cause for some of them to not being able to learn to read or sound out in their speech and language.*

Jennifer shared her perspective regarding the supports and resources she would need in the school to assist with the learning needs of deaf children and their families.

*I think the initial screening needs to be more precise and done often, more often than they are done. I think it should be done in early childhood before they actually come to school so that intervention can take place at an earlier age because by the time the student gets to school there may be a resistance to a kind of therapy or lessons or things they need to do to improve their articulation or speech or reading.*

Jennifer communicated her perspective on the current practice of waiting until school age for children to undergo hearing tests:

*I think that's a big mistake...I think it is critical to have every child tested when they are six months old, especially in the North. I think it would be a shame not to have a team, a team of people going around with proper screening material or instruments so that they can test the little kids that are six months old. Let's treat the child. Get them the best care. You can't tell me that there aren't children in here with hearing problems and none have been identified. That isn't even typical of a normal population. In 80 students here, wouldn't there be at least two children with some kind of hearing difficulties? You would think. It would be exceptional that none of our children have been identified with a hearing problem, extremely exceptional! It doesn't make sense!*

Jennifer shed some light on the process that would presently occur if a family decided that rather than sending their child to the School for the Deaf in Edmonton, their child should remain in the community. She addressed the Territorial Act on Inclusive Schools and its mandate to provide education to all children in the North regardless of ability. However, she noted that if there are no qualified professionals to work with deaf or disabled children, then the only way to access education is to leave

the community. Jennifer made the case that even if qualified professionals were abundant, they would not likely choose to live in an isolated community.

> *There is an Inclusive Schooling section of the Education [Act]. The school is obliged to provide schooling for all students regardless of their ability. For special needs students we would be obliged, actually legally obligated, to provide a signing teacher for that student and also if the student was partially deaf and needed a hearing aid system, then the teacher would have to be trained to use that system. Inclusive Schooling has been made mandatory. It includes people who are multiply handicapped, both physically and mentally, to be accommodated in the regular classroom with the other students. That said, it has in some cases, made a hardship on the school. First of all, because in some communities, there is certainly not the people available to take care of multiply handicapped children. In some cases, it requires a person with expertise. For deaf children, are there areas where a student would need to be cognizant of other dangers that we might deal with by hearing or seeing. For example, traffic through our schoolyard by snowmobiles where a deaf child may not be aware because he cannot hear them. It would be up to the school to protect the child from danger that would not necessarily be apparent to the child where there are services available. Here, if we could not get a proper caregiver in, say we had a multiply handicapped person, we would make every effort to accommodate that child in the school. If that was not possible, then I believe, I don't know, I would have to check out the Act, I believe it would be the obligation of the school board to provide care or education for that child where the service was available outside of the community. That is a big expense for the school board and a hardship for the family. Kids are away from the parents and in a way it's not fair. If there is an increase in deafness there will be a need for more skilled people to work with students who are hearing impaired. Teacher training does not always include that. If you have the skills, why would you work in an isolated community? In an isolated community, if you go through all of that training why would you want to have to come to an isolated community and have a really large class with a handicapped student and try to accommodate everyone without any kind of further assistance in the classroom. It would be really hard on a teacher who is skilled in signing to come into a situation where she has to really give her lessons so that she can teach the special needs person and also to control the classroom. It seems that unless there is a lot of support in the classroom, in the way of another person constantly, then it would be very hard for any person who is qualified to consider coming up to a situation and work harder. If you have a class with handicapped children down south, I don't know if they are limiting class size. But that would have to be one of the considerations up here if they discover there are a lot people with hearing problems, that you have to limit the class size because people need more individual attention and it would be difficult to give that to a person without extra support and help in the classroom.*

Jennifer commented on the quality and accessibility of educational resources on deafness in the Territories:

> *I think the website offers a lot. The nursing station certainly has materials. Education, culture and employment has a whole library full of materials that are available for information. At the board level they certainly are supportive of anybody who wants to learn more. If there is a conference and you want to go, we have professional improvement funds to help pay for some of the costs of that. We don't have an itinerant teacher specifically for deaf children. I think as your survey and awareness comes about, as there is an awareness that the need is there, to have more specialized education, then health and social services and the school and the parents need to lobby for more help not only at the early stages but also throughout the student's career as a student and to assist the student in becoming the best they can. Right now I think that the resources are adequate because there are so few identified deaf students that they are a unique situation so everybody finds out what they need to know right then and there about the situation. I am not sure how many people are aware about what deafness is and how do you help it. It may take a while for a stigma about deafness to go away. I am not sure if there is one but the fact that we don't have anybody identified as having a hearing problem brings me back to my first statement- it is really abnormal. It is like we don't have anybody wearing glasses. There should be at least ten kids at school wearing glasses. I think we're working along as a school, as a district, as the education ministry, making sure that special needs kids are included in the whole system rather than streamed away from the system. Health and social services may need to lobby for more funding, for more personnel, for more specific instruments, technical instruments, to identify students at an early age. Because we can give them all the support we want but it may be too late for the students to be thoroughly helped so we are back to early intervention. It is easier to test the five to six kids that are born each year [in the community] than to test the whole school of eighty kids ten years later. Pay now – pay later.*

Jennifer added further to her comments on appropriate placement in the education system. She noted that the key to parents' decision-making process is to make informed decisions based on all of the information available.

> *I think it depends on the acuteness of the deafness and also would the child benefit from learning to cope with their disability for a short period of time somewhere where they learn the basics of signing and then get back into a normal classroom. I don't think that deafness is catching. It's not a transmitted disease of any kind. And students also need to learn compassion. A student can*

*learn from seeing what other children are doing and they can also learn by making sure that somebody from their community is trained for it. I see that as a critical thing, a decision that parents need to take a look at very carefully. If there is not a person who can teach their child in the sign language then they have to be somewhere where that child can learn but I think that it's critical that that decision be made with the parents with all the information that there is.*

**George: A Community Wellness Perspective**

I met George standing outside the Co-op general store the day I arrived in Ehchuse. Denise, a northerner and a good friend whom I met at university during my graduate studies, knew George and had contacted George to let him know that I was coming to the community to do research. We started talking and when he realized who I was he said, "We've been waiting for you". Once we made that connection, I asked if it was possible to go with him one time to harvest caribou. That is how our friendship began to develop.

I decided to interview George about the general condition of hearing loss in the community, knowing that he would be able to speak to the subject from personal experience as he has endured a hearing loss for several years and has family members with hearing loss. Although this is a departure from the original thesis question, I was aware of the community's desire to study hearing loss not only in children but also in adults and elders. I felt that it was important to include a voice that would illustrate the community's concern.

The audiologist had informed George that he had inner ear damage. He speculated on how the damage occurred:

*Well just noise. From skidoos and chain saws and things that I used most of my life. I think the last rifle that I had was a 270, and I found that one really loud. I guess for me sometimes other people hear skidoos and motors. I'm not the first one to hear it. I mean those things don't bother me. It's the animals – I can't hear the animals, caribou and moose, there is a lot of observation, looking for tracks. So, I get scared because I can't hear them, especially in the fall time, like with the animals, especially moose, because they mate in the fall time. There were some of the elders in town in the 1920s, not too long ago, they were going through Fort Resolution by canoe and they were paddling and they camped on one island. One of the elders told a young man 'lets go look for moose', so they went off together. They started walking up and walking along the hill. The elder stopped all of a sudden and asked the young man 'do you hear something?' The young man said 'no'. The elder said 'I can hear the moose chewing.' To be able to hear a moose chew, that's really amazing. For me, the amazing thing is that even though they were elders, they still had good hearing. They have that knowledge.*

Both George and his father suffer from hearing loss. He shared his experience with his father's hearing loss and some of the issues that he faces in dealing with his own hearing loss.

*I have to repeat myself. Sometimes it does get frustrating. I think at the same time it is important that they understand what we are saying. I think for people like my dad, elders, we rely on a lot of information from the elders. I know for some of us who went to college and that, we tend to use a lot of research papers. We don't have any from our own people. So to us, they are a wealth of information. That's why it is important that they understand what we are saying. The frustration comes from having to repeat. But I think, for my dad, he doesn't use a hearing aid. Sometimes he says the wrong things from what you want to ask him – his response. Sometimes for me too. At this last meeting I went to in Yellowknife, all through the discussion we were in the circle. They came to me and asked me what I thought and I thought they were talking about something else and so I responded to that and they said we are talking about something else. They always tell me to get a hearing aid! I think they get frustrated too. I have a hearing aid too. I got it about a month ago. But I put it in my ear and it screeches. I went to the audiologist and I explained the problem. But when it works it is really clear. I guess I am going to have to start using it. But I didn't want to use it the first time.*

George revealed some of the feelings he has experienced when he doesn't hear what other people are saying.

*In some cases, for me, I kind of wonder if this is the proper thing to say. But the people that I am with here, we all know each other, so we joke around and laugh. So it is okay there. But if I go to workshops, most of the time they don't use a sound system. So for me, if I don't hear what's going on, I don't know. I am losing out on something important ... if I don't know what is going on ... I am missing information. My information may not be accurate.*

George discussed some of the strategies that he has developed on his own to cope with various situations and shared ideas about how to deal with a large group situation.

*Normally, like I said with people that I know I sometimes just ask them to find out what other people are saying. They're pretty good that way. Like if there's a sound system I can still follow it. So that can be lonely when you don't hear things. Like I try to sit close to the speakers and make sure that the audio sound systems are turned up. I think getting to be aware is the most important thing and what you can do. Like even the work that I have, I still have a problem. I think the most important part of it is...people have to be patient with them. It's a lot of different kinds of emotions when you are dealing with a deaf person or hard of hearing. You've got to have patience. Like some of our elders there, we have to listen to them. And so like again they are our source of information, lots of traditional knowledge, all this cultural stuff and some day, like it's not going to be like that. We are going to lose our source information. And I think they are patient. To me that's the way that I look at it, if a person wants information they have to be patient and respectful. I think in this community people understand that with the elders. But I think it is an individual thing. If you want to understand something and you are patient enough you're going to get it. Maybe a person who's hard of hearing might not get it the first time. But sometimes they come back and say this is what you were talking about last time. I think that's the thing about hard of hearing people – being respectful about their hearing loss. Like I know it does get frustrating at times but if people can understand that. I think sometimes we miss out on lots, when you are hard of hearing. Sometimes you have to ask questions about what is going on.*

George's experience with community, support services, resources, and educational material about hearing loss prevention was limited. However, he recognized the importance of hearing protection and the changes that have come about with the development of new technology.

*I haven't seen any. I think it's important. So, I'm sure people knew how to take care of their ears before with traditional healing but nowadays there is so much noise and noise pollution. I think it's important that people are aware of damage*

*that different noises from things like chainsaws, skidoos, and motors can make and there's always noise. Sometimes you have that ringing in your ears after. So I think it's an awareness about the damage it can cause. You can get some pretty good earplugs now. You can hear the sound but it's muffled, the sound. People should be aware of the facts.*

Although the main focus of our conversation was on hearing loss in adults and elders in the community, the issue of sign language surfaced and whether it would be useful to have some knowledge of ASL in the community.

*It would be good because we have one member who can't hear – Arthur. So for him, like out of respect, I think that we should learn how to use sign language.*

**Conclusion**

The participants in this study revealed that the resources, supports, and services available for deaf children, parents, families, and the community were insufficient while Sandra and her family were in the community and continue to be inadequate. The participants' responses to a community member's deafness were consistent in terms of the desire to re-establish relationships, break down communication and cultural barriers, and create an accessible environment. All of the participants, regardless of their professional or personal relationship with Arthur, were emphatic about the need for better quality resources, supports, and services in their community and across the Territory.

Although Sandra and her family no longer live in Ehchuse, she and the community at large commented on the importance of conducting this study to serve the interests of other northern parents with deaf children in isolated communities. Furthermore, the community expressed another related hearing issue that had immediate

community relevance for consideration. Hearing loss not only among children but also among those who are middle-aged and older is a grave concern. Many of the elders in Ehchuse have suffered hearing loss and they are becoming less accessible to the youth at a time when the wisdom of the elders is very much in demand.

The following chapter contains my analysis of the participants' perspectives regarding the research question.

## Chapter Five

## Analysis of the Data

### Introduction

In the preceding chapter, I presented different voices from one community in the Northwest Territories in an attempt to detail the personal stories and community struggles as a result of having one deaf member in that community. Those interviewed include individuals closest to the deaf person including both immediate and extended family members, who are linked by family ties but separated by interpersonal as well as physical distance that increased over time - and those with only an obligatory professional relationship which demanded a certain degree of service but which was intermittent based on distance and high turnover of care givers who came and went as they sought professional opportunities in the North and elsewhere. In essence, it appears that there is a service being provided but in reality, the health system and those individuals working within it, failed to provide the necessary services. In this chapter I address, from my perspective, the themes that emerged from the northern voices heard in this study. This inquiry also uncovered a growing problem of hearing loss associated with occupational and environmental noise.

### Themes from the Literature

As noted in Chapter Two, the epidemiological and medical literature describes a high incidence of hearing loss across the circumpolar North, including Canada. When I began the study, I was not aware of this medical observation. After scanning the available literature, I identified a number of studies dealing with chronic otitis media,

which can lead to hearing loss in children[22]. This phenomenon is (certainly) evident in this study.

The literature regarding the role of Aboriginal parents in their children's health and education describes in considerable detail the impact residential schooling has had on many individuals who attended such institutions. For many, institutionalization has had a lingering negative effect long after leaving the institution. During the period in residential school, the Aboriginal students, for the most part, were not exposed to being parented or seeing effective parenting skills modelled in the institutions by the staff thus the experience there has lead to a second generation of children being affected by the residential school experience. It can be argued that the oppressive conditions under which children were raised in these residential schools and the air of superiority demonstrated by many of the school authorities who were attempting to "civilize" Aboriginal peoples contributed in part to compliant behaviour to white authority by many former residents of these schools (Smith, 1999). Health services were considered an important factor in the assimilation policy in terms of raising Aboriginal peoples from the position of dependency on the state to full citizenship (Young, 1988). The schools and the health care system are examples of systematic tools used by the Euro-Canadian government to assimilate Aboriginal peoples. In terms of health, it is still true today that the general public, including Aboriginal and non-Aboriginal people, is deferential to medical opinion, as medical practitioners hold positions of power.

[22] See Chapter 2, page 28-30 for examples.

Access to services, supports, and resources in the Northwest Territories is significantly different from that available in the south in terms of the range of services and response rate. This limited range of services and delays in response may be due to distance, isolation, and the high cost of delivering these resources. It may also be impacted by a shortage of professionals willing to serve in a region that requires considerable travel in less than ideal conditions. Individual professionals may not be willing to work in a cross cultural setting. It may also have to do with systemic racism embedded within our health care system, racism, which exists in all corners of our society (Georgetti, 1997, Canadian Council for Refugees, 1996). Racism is often unarticulated and unconscious within the mind of those who hold racist attitudes. Those who hold racist views often vigorously deny racism, however, racism continues to infect our lives. Reflection on systemic racism in the North and in particular in the community discussed in this case study is necessary to the analysis concerning the medical response to parental concerns regarding child health in the community. There are countless examples of racism in schools across the Northwest Territories. Let me give you a composite example of how I saw this happening. I was visiting a classroom at Fort Tukak[23] when the non-Aboriginal teacher, in the presence of Aboriginal students, made this remark, "Just look at them – you can't teach them anything." Then on another occasion, I heard a school staff member say, "This is just a waste of time. I don't know why I bother. They are like this in every northern community I go to". These remarks were disparaging and sweeping generalizations about the students' lack of skills, abilities, and knowledge. I noticed that the students clearly heard the comments and were obviously affected by them. The students, who were typical

[23] A fictional community.

boisterous grade school students, quickly became very quiet and with their heads lowered, looked sideways at each other. Minutes later, they were back to being cheerful and buoyant. However, regardless of their prompt dismissal of such comments, hearing these racist comments on a regular basis (which is often the case) has an enormously damaging impact on any individual or community.

Historically nurses who are born, raised, and educated in the south have staffed the nursing station in Ehchuse. They normally move in and out of Ehchuse on a three-month rotational basis. A number of issues emerge from this fact. First, there would have likely been no formal cross cultural awareness or sensitivity training provided in the nursing programs at that time. Nurses going to northern communities for the first time undoubtedly experienced culture shock. Because most nurses were stationed in communities on a rotational basis, they were never in one community long enough to move beyond culture shock to cultural relativism and cross cultural understanding nor were they able to develop long-term relationships with the people. Second, the nurse as "authority figure" within the community would have had a significant impact on patient - heath care worker relationships. The authority to determine evacuation in terms of medical emergencies was, and continues to be, the nurse's responsibility. Because of the high status given to nurses in the community, challenges to that authority would have been rare.

I examined the social networks and coping strategies among hearing parents with deaf children. The literature points to a need for hearing parents with deaf children

to have ongoing access to other hearing parents with deaf children in order to share similar experiences, to talk about challenges and successes, and to gain insight into their child's experience. New parents do not have the support of other parents with older deaf children to ask questions about behaviour, language, culture, and education. Asking these questions and hearing responses from a number of parents who have experienced similar uncertainties is critical, particularly around the time of diagnosis, as it alleviates some of the enormous stress parents go through during this stage. In addition, delays in a child's language acquisition can have a significant negative impact on the child's language, cognition, and social and emotional development. Further, deaf adult role models are consistently identified in the literature as having a positive influence on hearing parents' ability to cope. Deaf role models are particularly important for both deaf children and their hearing parents. During the time that Arthur was in the community, he had no access to a deaf adult role model. Similar to the theme relating to peer groups, young people need adults to whom they can relate, with whom they share something in common, and whom they respect as mentors. Parents also need a deaf adult with whom they can discuss their concerns about growing up deaf in a hearing world. There are some breakthroughs in northern communities regarding adult deaf role models. For example, during my career as an interpreter, I was aware that the Deaf community in Winnipeg was concerned with the lack of support in northern Manitoba communities for deaf children. Through formal channels, they began to offer language training, cultural awareness, and mentorship services provided by qualified Deaf adults in these remote communities in Northern Manitoba. Some communities in the Northwest Territories and Nunavut are also engaging in cross

cultural awareness with the Deaf community. However, the further north that one must travel, the less likely it is that a Deaf adult will be interested in this service. The Deaf mentor experiences the same challenges of working in the North, as do other professionals. Without support from other hearing parents and Deaf adults, as is the case in Ehchuse, parents, family members, and community members may continue to find themselves isolated and alone. I was also interested in examining how a family copes with deafness, especially the extended family dynamics when a deaf child has become part of the family. Often the extended family feels confused and uncertain as to how they can be involved with the deaf child's life and express frustration regarding a lack of information about deafness.

Finally, I investigated the importance of early medical diagnosis and early language acquisition among deaf children. As noted in Chapter II, the literature consistently supports the need for early diagnosis. In fact, deaf infants are often not diagnosed for several months. This happens as parents are often unaware of hearing loss in children, particularly if the child is their first child or if there is no history of deafness in the family. When parents begin to suspect that there might be a problem with their child's hearing, they often deny the problem for a period of time before seeking medical confirmation. Once the parents seek medical advice, health care professionals may delay diagnosis for a number of reasons including the fact that the family lives a great distance from the necessary testing facilities, the child may have a current ear infection that impacts test results, waiting lists for access to appropriate testing equipment, and uncertainty pertaining to test results. Beyond the delay in diagnosis, there may be

further delays in accessing services. Comparing the North to southern Canada, the delays increase exponentially. In southern cities, parents have immediate access to a range of resources. In the North, there was one audiologist for the entire territory!

**Parental Perspective: Themes Emerging from the Data**

After analyzing the data, I identified several themes that surfaced from hearing the parental perspective and several more themes surfaced from hearing the extended family perspective, the community perspective, and the professional perspective. Some of these themes overlap with each of these four perspectives and some stand alone, unique to that perspective and not mentioned elsewhere. The literature also raises themes, some of which are also identified in the different perspectives. The first of these perspectives is the parental perspective on having a deaf child in a northern community. Sandra, a parent of a deaf child who became widowed early in the child's life, described the problems she was confronted with, the emotions she felt, the challenges she experienced, and the decisions she made from the time her infant son was diagnosed as deaf until the present. In my interpretation of Sandra's story, I was aware of four emerging themes regarding her experience. The first theme I identified was trust in professional medical opinion versus parental intuition. According to Sandra, doctors and nurses at the nursing station were not responding to her and John's concerns with the same degree of urgency that they, as parents, felt when their son first became ill and on subsequent visits to the nursing station. Sandra and John instinctively recognized that there was something wrong with their son and felt that the methods of medical intervention were not working.

*Sandra: It was my first time you know, my first child...His father was scared too.*

They pressed the medical workers to try alternative practices and initially questioned the methods but the professional response was minimal and placating.

*Sandra: And again, they just gave me antibiotics. I would give him that but I thought this antibiotic isn't going to help and shouldn't we try something else. But they never did.*

Parents, in general, often indicate intuitive awareness of their children's health problems and yet often downplay their own awareness and defer to professional medical opinion. As stated earlier, systemic issues of racism such as differential treatment and inaccessibility (Georgetti, 1997) clearly exist in the health care system and response rates by health care professionals in Aboriginal communities may be substandard in comparison to the health care provided in non-Aboriginal communities.

*Beth: the parents had had concerns, they had gone to the nursing station and were told, 'oh she has an ear infection, we'll wait until the ear infection goes by.'...], it was two years before she got diagnosed.*

Arthur was not born deaf; he became deaf post-natally, likely as a result of chronic otitis media, given its high incidence and the prevalence of hearing loss in the North. Arthur's deafness likely may have been prevented given the proper medical attention.

*Sandra: The doctor said when this thing started, if they had just taken him into the hospital in Yellowknife, pumped out his ears, kept him at the hospital and treated him instead of taking him back and forth it would have been prevented, his ears wouldn't have been damaged.*

A second theme strongly relates to the previous issue. The theme is one of professional medical influence versus extended family influence. Both parties had very different perspectives to offer the parents regarding the options for their deaf son in this

case study. On the one hand, general professional opinion was to send their deaf son to southern Canada and a residential school placement. On the other hand, the extended family, both the maternal and paternal grandparents entreated the parents to keep their deaf son in the community arguing that the residential school placement was too far away and that their grandson was too young.

> *Sandra: We had to sit down and talk with our parents – that's when they said no.*

Despite the strong influence the extended family had on Sandra and John, professional medical opinion swayed their decision. Upon mutual agreement, the parents decided to send Arthur at the age of six to the school for the Deaf in Edmonton for one year. This involved a difficult relocation for Arthur. Edmonton is approximately 1500 kilometres from Ehchuse. Travel involves a one-hour flight by bush plane followed by an hour and a half commercial scheduled flight into Edmonton. The first year of separation proved very difficult. At the end of that school year, Sandra and John decided not to send Arthur back as the separation was too upsetting for the family and for Arthur.

> *Sandra: We said no we are not sending him away again.*

A third theme concerns the social support needed by a family when a child with special needs, such as deafness, is introduced into the family. It appears that after John (Arthur's father) died Sandra found she did not have the support she needed from family members and friends to cope with the death of her husband, a deaf son, and three younger hearing children.

> *Sandra: I couldn't handle it. I was left with four children, with a baby and two toddlers and Arthur.*

This lack of support is a common occurrence as family members and friends often experience turbulent emotions such as fear and apprehension during and after critical life events.

> *Sandra: In the community, his grandparents were there all right but it was also hard for the grandparents because they don't know how to deal with him.*

If support from the family is not provided or if the family fragments for whatever reason, external support networks are critical. Social support and information provided by friends, relatives, and experts could have lessened the degree of distress Sandra experienced during this critical time. As it was, Sandra was left without external networks to turn to because she was living in a small, isolated, northern community that did not have access to professional support. Despite the fact that no external social support was available, Sandra continued to fight for her child's rights and her own rights as a parent with a deaf son in terms of services, supports, and resources.

> *Sandra: During all that struggle I went through an interview with CBC and anything to get noticed so that we could get something for people like him.*

A fourth theme relates to the loss of traditional lifestyle, Dene culture and values, the Chipewyan language, and interpersonal familial relationships. These elements were not accessible during the time Arthur was in Edmonton at the school for the Deaf. However, after Arthur's first year at the school for the Deaf, the family was reunited for the winter and Arthur was able to spend time with his father on the land learning long-established Dene skills, including hunting and fishing.

> *Sandra: He managed to spend that whole year with his dad.*

*Joe: Before I die, I'd like to see my grandchild. The summer time coming here would be good. We could go for a picnic.*

Arthur then returned to Edmonton and remained there for several years. When he did return to Ehchuse, there was no one there who knew sign language, which meant that none of his family members or peers were able to communicate with him. While Arthur was in the school, he was taught ASL and Deaf culture but he was not exposed to his own cultural beliefs and practices or Chipewyan, the first language of many community members, including his only living grandparent.

*Sandra: His grandparents used to sing to him when he was just a little baby...in their [Chipewyan] language.*

It was very frustrating not just for the family but the entire community.

*Carolin: He needs to come back to the roots... to learn this (Chipewyan) language...go out on the land...make a fire...do cultural stuff.*

*Tarah: I would like to see this one learn his language so that he can even speak up at a general public meeting and say what he wants... It's his culture... his first language and it is a very important language that should be passed on.*

A fifth theme relates to the impact of John's death on Sandra in terms of coping with his death and becoming the sole decision-maker in the family. This event put tremendous pressure on Sandra.

*Sandra: I am here myself now but John's not here with me anymore.*

Sandra and John had been extremely frustrated at not being able to get what they needed in the community. During the year that Arthur was home in the community, Sandra and John had tried to set up services for their son at the school.

*Sandra: We had to have a lot of patience and a lot of hope that something would happen that – but how many years now?*

Despite the Special Needs Education Policy, which began in 1986 and assured that children with special needs could remain in their home communities, services remained unavailable in Ehchuse. This policy took effect at approximately the same time Arthur first went to the school for the Deaf in Edmonton. Policy without the means to implement it is meaningless. When John passed away, Sandra was left with four children all under the age of eight. At that time, she decided the best viable option for Arthur was to send him back to the school for the Deaf.

The final theme concerns the belief that parents with either family support or external support have a more positive relationship with their deaf child than those who lack either of these supports. Receiving support as soon as possible after the diagnosis of a child's deafness is critical. The level of support that parents receive from their extended families, friends, and professionals clearly has a strong impact on the quality of parent-child relationships. Regardless of these conclusions drawn from other studies[24], in this particular case study, Sandra appears to have maintained a positive relationship with her deaf son and continues to fight for her rights as a parent and her son's right to access educational support.

> *Sandra: I want him to stay here in Yellowknife where we live now... I just want to be close to my family.*

**Perspectives from the Extended Family: Themes Emerging from the Data**

The second perspective from the data centres on the extended family. One theme that emerged from this data was the impact of Arthur's absence. It has had a

[24] See Chapter 2, page 36 - 38

significant impact on not just the immediate family but also the extended family and the entire community.

*Carolin: I feel sad about that there is no contact with him.*

In this case, the family first relocated their deaf son to a large, urban centre to access resources, services, and support networks. Then, and this is not uncommon, the nuclear family moved to an urban centre to be closer to their child.

A second theme relates to the understanding that most families experience significant change when an infant with special needs such as deafness enters the family. Sandra and John, like most new parents, were required to learn an enormous amount, not just about general parenting but also about the extensive care and support their child needed. As noted above extended family members may experience turmoil, fear, and apprehension during this initial stage after diagnosis. This was clearly the case for the extended family members participating in this study.

*Sandra: They just want to smother him with their love but they don't know how to deal with him you know?*

The extended family may have felt hesitant and unsure as to how they could be involved in Arthur's life. There was no professional support offered to the extended family in terms of coping with a family member who was different.

*Carolin: I wouldn't mind learning sign language - basic signs even, so I can learn about my nephew too - just where [he is] coming from.*

As a result, they encountered an ever-widening gulf in the relationship between themselves and Arthur.

A third theme that surfaced from the data is the exclusion of the extended family from professional medical and educational discussions regarding deafness. Only Sandra or John went to Yellowknife for the initial diagnosis, for subsequent medical appointments, and to access auxiliary services. The parents were flooded with information on deafness in a short period of time regarding deafness. The extended family was not part of this process. They did not have the opportunity to talk with professional health care workers about what it means to be deaf, how they could help, and how they might continue to play a role in their grandson's, nephew's, and/or cousin's life.

> *Carolin: Even me, I don't know that much... so if we had more... information...That would be great... I don't have the answers.*

Consequently, they expressed frustration regarding a lack of information about deafness and were underutilized in terms of involvement with Arthur.

**Community Perspectives: Themes Emerging from the Data**

In general, the public lacks understanding of deafness. Deafness is often equated to mental disability or confused with other disabilities. For example, I can recall countless times being asked if I, as an interpreter for the Deaf, could read Braille for the Blind, if Deaf people could drive, and if Deaf people could have children. During my interpreting career, often a hearing client (a person who hires an interpreter so that they can communicate with a deaf individual) would have had no exposure to a Deaf person prior to the appointment and have little knowledge about deafness. As such, hearing clients frequently made assumptions regarding the cognitive and physical abilities of the Deaf person based on the distinctive hand movements, facial expressions, and "Deaf

voice". Deaf people have functioning vocal cords, however, they are not exposed to sound and thus are not able to produce the same sounds as a hearing person because they lack phonetic training. Hearing individuals who are unfamiliar with these aspects of how Deaf people communicate can be intimidated or put off. They may not know how to respond and they may be concerned with their own ability to communicate or respond. The general public, in fact, does not conceive of a Deaf cultural and linguistic identity. The community of Ehchuse was no different than the general population regarding awareness about Deaf identity.

> *Sandra: People used to call him retarded... Other kids would pick on him or bother him.*

Like the general population, many of the friends, extended family members, and those in professional roles in the community were at a loss as to how to help.

A second theme relates to a sense of frustration and sadness experienced by the community as a whole because they were not able to provide the services needed by one of their community members.

> *Tarah: There was nobody who could do anything – it was very sad...We couldn't provide the service for him.*

The community had tried very hard to bring qualified people to Ehchuse. The family and the community wanted more than just sporadic service and support in or from Yellowknife. They wanted one-on-one service and support in the community.

> *Tarah: If a deaf person wants to move back here, there is no communication, no sign language, there's absolutely nothing for him, no services available and I am part of that professional team and I have absolutely nothing.*

Despite the community's emotional involvement and the effort to realize these services, the family was forced to leave the community and, in essence, relationships were severed. On reflection, many of the participants expressed remorse over the separation and eventual ending of this relationship with one of their community members.

The final theme from the community perspective is associated with peer group interaction. Arthur's peer group in the community did not share a common language with him, thus making it challenging for any same-age interaction at school or at play to occur.

> *Tarah: Now he is a teenager, I can just imagine and feel how it feels like there is no communication with his peer group... like he is totally lost if he ever comes back.*

It is important for people to have positive relationships in their lives not just with adults but also with peer groups. Peer groups give young people an opportunity to be on an equal footing with others and an opportunity to gain experience with interpersonal relationships.

> *Tarah: My wish would be to have all... the deaf [in] all the communities... communicate through computers in each community... That they have something to go to and use this computer to ...communicate with... another deaf child...like pen pals and they could write to each other with email.*

**Professional/Medical/Social Support Perspective: Themes Emerging from the Data**

The professional, medical, and social support perspective has several associated themes. The first of these themes is the documented fact that there is a high incidence of chronic otitis media among children in the circumpolar north, which can lead to

hearing loss[25]. Although this study focuses on only one case of a young person with a hearing loss in Ehchuse, it is clear that there is concern from the community and the professional sector that others may be present in the community and across the Territories that are as yet undiagnosed.

> *Jennifer: the fact that we don't have anybody identified as having a hearing problem... it is really abnormal.*

This leads to the second theme regarding the importance of early diagnosis. The call for universal screening of all infants cannot come soon enough. At the time data collection took place, universal screening of all infants born in Yellowknife had become policy although personnel at the audiology centre still required proper training on the equipment. Many expectant mothers are now evacuated to Yellowknife for the birth of their child and will therefore have the benefit of early screening. However, there are many mothers who give birth in other communities in the Northwest Territories.

> *Beth: It's not a universal screening program because it's not for all the babies that are born in the Territories but at least they can get quite a few and [Stanton Hospital] has the highest birth rate in all the hospitals.*

In addition, there are many children under school age who have not had hearing tests and there may still be deaf children falling through the cracks.

> *Jennifer: It would be exceptional that none of our children have been identified with a hearing problem, extremely exceptional!*

A third theme, which relates to early screening and diagnosis, is the importance of language acquisition among children regardless of the language chosen by the parents.

---

[25] See Chapter 2, page 28 – 30.

*Jennifer: I think it is critical to have every child tested when they are six months old, especially in the North.*

Once diagnosis has occurred, parents need immediate access to information regarding their child's difference, their child's needs, their needs as parents, and their right to use supports, services, and resources in order to make informed, educated decisions regarding language use at home and the type of school environment that will provide essential language education.

*Jennifer: It's critical that that decision be made with the parents with all the information that there is.*

Clearly, the health care system failed to communicate to Sandra and John concerning Arthur's health, his subsequent hearing loss, and the services available for the family in the community.

A fourth theme relates to the high incidence of permanent ear damage leading to hearing loss in mature adults and elders in this community and in many other communities across the Northwest Territories. Ehchuse, through its own local observations, has identified this serious community physical and social health concern. This issue was raised on numerous occasions during my stay in Ehchuse. Loss of hearing can have significant consequences on northern communities. Hunters who have a hearing loss are at greater risk of occupational and environmental hazards while on the land as they may not be able to hear other hunters or animals in their vicinity. Hearing loss is also of social concern, particularly in terms of multigenerational relationships. Elders and youth in the community have reduced communication as a result of elders' with hearing loss.

*George: Our elders... we have to listen to them... they are our source of information, lots of traditional knowledge, all this cultural stuff and some day, like it's not going to be like that.*

Elders are important links in maintaining the culture, which have often been lost by younger generations who were removed from their families and communities to attend residential schools. Had this study been community-driven rather than community-based, it might have examined this issue of hearing loss in adults and elders with a greater level of involvement from the community. It became clear to me that dealing with this issue was, in fact, more immediate to the community than the issue of a deaf child who had been part of the community a decade ago.

A fifth theme concerns the lack of qualified health care professionals in the community. There were delays in or absences of professional services and resources during the prevention and treatment stages when Sandra and John were taking their son back and forth to the nursing station and Stanton Hospital in Yellowknife as well as during the subsequent intervention stage once Arthur had been diagnosed as deaf.

*Beth: I know that one little girl that's in [a northern community], it was two years before she got diagnosed.*

This can, in part, be contributed to transitory rotations and low retention rates of qualified personnel not just in the community but also throughout the Territories.

*Beth: If you don't know yourself, how are you going to carry out the program right? And in a community there is the nurses but they don't have a clue about that either. And another problem is turn-over, every time you go to the nursing station there's a different nurse in there and you talk to them...and then they're gone, right.*

In addition, there was no opportunity for Sandra or John to seek a second opinion given their isolated geographic location. Historically and at present, the general public is

often hesitant about challenging medical opinion or to seek answers to questions they might have regarding a diagnosis or treatment. The data collected points to the failure of the health care system in that the professional personnel should have recognized Arthur's health status, taken preventative measures, and followed-up with appropriate treatment. Even now, the Community Health Representative expressed concern for being able to provide an environment of inclusion for deaf community members.

> *Tarah: If a deaf person wants to move back here, there is no communication, no sign language, there's absolutely nothing for him, no services available and I am part of that professional team and I have absolutely nothing.*

The sixth theme relates to the education system and the scarcity of qualified special needs professionals in the Northwest Territories. This scarcity is even more pronounced in isolated communities within the Territories.

> *Beth: they don't have the support and services for speech and language stimulation that they need when they are in the communities.*

As indicated earlier in this study, there was a period in Ehchuse when an interim teacher located at the school had some exposure to sign language and was able to communicate with Arthur. However, this teacher did not remain in the community and Arthur was once again without access to information, education, or the Dene way of life. A policy regarding a Special Needs Education Program was established in 1986 in the Northwest Territories. The program was designed to allow children with special needs, such as deafness, to remain at home in their communities. This policy was established at approximately the same time the professional sector was urging Sandra and John to send Arthur to the school for the Deaf in Edmonton. Attempts were made to train local

people from Ehchuse to communicate using ASL but problems arose. First, the training occurred in Edmonton and the attractions of the big city meant that some of the participants failed to apply themselves to the training. Second, those involved in the training did not necessarily have the same degree of motivation to learn a new language, as did Arthur's immediate family members for whom the language training would have direct relevance. Third, the training course was only a few weeks in duration. As a student of ASL and then as an instructor of interpreters, I can state with confidence that learning functional ASL, like any second language, requires immersion in the language and culture for no less than a year and that acquiring fluency requires at least four years. Associated with the amount of time spent learning a language is the amount of time spent using the language after learning it. If a person does not regularly use his or her second language, particularly with native users of that language, that person will very quickly lose his or her ability to communicate in that language. Clearly, the education system failed to provide the supports that Arthur needed to remain in the community. Even now, the professional opinion is inclined to encourage families to relocate in the south.

> *Beth: The services aren't here, your best option is to go down south... but they don't want to leave their community either.*

A seventh theme emerging from the data relates to how professionals, recruited in southern Canada, experience the North. For many, the experience can be very isolating. Nurses and teachers going to northern communities undoubtedly experience culture shock even though they may not use the term "culture shock" to describe their

experience. They may indicate that they are stressed out, feel overworked, and have difficulty coping. These feelings are typical of culture shock.

> *Beth: All the other [professionals] tend to have a real problem with people not showing up for their appointments or they'll go back six months later and nothing has been done and the recommendations haven't been followed through...it's frustrating. And that's [another] problem up here as well, especially for the nurses, they're not getting compensated anymore and the garbage they have to put up with in the community...I mean every three to six months they've got new nurses up there.*

In both large and small communities, non-Aboriginal people tend to gravitate to other non-Aboriginal people and do not interact with local community members except during business hours. This self-isolating behaviour insulates them from local people. By remaining within their own cultural network, these individuals do not move beyond culture shock to cultural relativism and cross cultural understanding nor do they develop strong, lasting relationships with community members. The stress of being in an understaffed environment would have also had a significant impact on those external professionals working in the northern communities. Clearly the health and education systems and the professionals working within these systems were not integrated into the community nor were there locally trained health and education professionals during the time Arthur was in the community.

The final theme relates to organized networks for parents of deaf children in the Northwest Territories. At the time of this study, no formal network has been established to provide opportunities for parents to share their experiences with one another so that they are better able to cope with having a deaf child. Sandra made it

clear from the beginning that she agreed to participate in this study based on her desire to help other parents in the Territories gain a better understanding of her experience.

> *Sandra: He may be the only one I know who is Deaf but I am sure there are other parents who are going through what I am going through.*

Parents like Sandra pave the way for parents with newly diagnosed deaf infants by sharing their experiences with obstacles, barriers, breakthroughs, and the accomplishments of their deaf children

**Conclusion**

In this chapter I have addressed emerging themes that have arisen from the northern voices heard in this study. The four perspectives; parents, extended family, community, and professional/medical/social supports and services, as well as the associated themes conceivably represent this Dene community's situated response to having a deaf child in the community.

The following chapter includes a synthesis of some of the ways that one community member's deafness has had an impact on the community. Recommendations from the community and myself regarding how others might manage in similar situations are provided. Also addressed are methodological reflections and suggestions for further research.

# Chapter 6

## Conclusions and Reflections

### Introduction

In this chapter, I summarize and synthesize one Dene community's situated response to deafness. I present recommendations, proposed by community members, for change regarding the response to deafness when it occurs in northern communities. I also present my own recommendations regarding how other families and communities might manage in similar situations. I provide evidence that the issue of deafness is a growing concern in Ehchuse, and other communities across the North. Theoretical and methodological reflections and suggestions for further research are included. I discuss the importance of reporting back to communities involved in a partnership with a researcher and describe how I reported back to Ehchuse. Finally, I reflect on my experience as an external researcher conducting a cross cultural inquiry in a Dene community.

### Summary of the Study

Chapter One was an introduction to this thesis, which was based on a cross cultural case study regarding a Dene community's response to having a deaf child in the community. I investigated what support was provided to those who had to deal with deafness once it was diagnosed and inquired as to what information was and is needed to address the challenges of a parent, extended family and community in raising a child who is deaf in a small, isolated, northern community. The consequences of unavailable professional support or inadequate educational materials on deafness are severe,

including delays in language, social, cultural, and cognitive development of deaf children. The health care system is responsible for educating those people who are affected by deafness, including the immediate and extended family as well as the community, about the significant decisions that must be made when hearing loss is identified and the implications of those decisions. Accurate and culturally relevant material must be immediately available. My involvement in the Deaf community for several years and my academic pursuits in Native Studies were the starting point that led to the question that guided this study: What has been this Dene community's situated response to having a deaf child in the community?

Chapter Two addressed the theoretical framework used in this study, which situated deafness as a cultural identity rather than a medical pathology or a disability. This chapter also described the services available to Aboriginal people in the North and it described the experiences commonly shared by hearing parents when faced with the medical diagnosis of having a deaf child, including the social support systems that are available and the issues that are raised regarding language and education. In addition, Chapter Two provided an overview of relevant literature.

Chapter Three provided a definition and a description of the research methodology and methods used to conduct this community case study. The primary methods of data collection included interviewing, observation, informal and formal community meetings, and critical reflection. The interviews were open ended, with an effort to keep them as informal as possible in order to provide an informal relaxed

atmosphere. I described the setting for the community case study, including a historical, physical, and cultural description of the community. I also addressed issues involved in obtaining permission from the community to conduct the study, of building good rapport, and gaining informed consent from individual participants.

Chapter Four was a presentation of voices from the family, community, and the professional body regarding their response to having a deaf child in the community. I brought together different voices by relating personal experiences and including quotes at length from interviews with participants in an attempt to detail personal stories and community struggles regarding deafness. The participants revealed a desire to re-establish relationships, remove communication and cultural barriers, and create an accessible environment for all community members. There was a clearly expressed need for improved resources, services, and supports in their community and across the Territories regarding not only deafness in children but also hearing loss in adults and elders.

In Chapter Five, I shared my perspective on themes from the four perspectives that emerged as I analyzed the data. Some of these themes overlapped with each of these perspectives and some stood alone, unique to that perspective and not mentioned elsewhere. The literature also raised themes, some of which are also identified in the different perspectives. The following table represents the themes identified in the previous chapter:

Table 1

| **Parental Perspective** |
|---|
| 1. Trust in professional medical opinion versus parental intuition<br>2. Professional medical influence versus extended family influence<br>3. Social support for families with special needs<br>4. Original identity is lost<br>5. Single parenthood, in this case, made it more difficult to cope with the<br>6. Degree of support for parents with a deaf child in the community |
| **Extended Family** |
| 1. Impact of child's absence on the extended family<br>2. Extended family's experience regarding deafness and how they might be included and involved in their deaf relative's life<br>3. Lack of professional support and information that would ideally aid in understanding the impact of a deaf child on the family |
| **Community Perspective** |
| 1. The community's lack of understanding regarding deafness as a cultural identity and lack of knowledge regarding ASL<br>2. The community's sense of frustration and sadness at losing a community member due to lack of resources<br>3. Absence of a peer group within the community |
| **Professional/Medical/Social Supports and Services** |
| 1. High incidence of chronic otitis media among children in the circumpolar north<br>2. Recognized need for early diagnosis regarding hearing loss among northern children<br>3. The importance placed on early language acquisition among children with a hearing loss be it ASL or English<br>4. High incidence of permanent ear damage leading to hearing loss in mature adults and elders in the North<br>5. Lack of qualified medical personnel able to deal with hearing loss during the time the deaf individual in this study was in the community<br>6. Lack of qualified personnel in the education system able to deal with hearing loss during the time the deaf individual was in the community<br>7. Lack of integration between the health and education systems and this northern community<br>8. Lack of organized support networks in the North for parents with deaf children<br>9. Lack of adult deaf role models in the North for families with deaf children |

**Implications**

The message from this case study is clear. If the territorial government does not change its response to northern families with deaf members, it will continue to fail in meeting their needs. Infrastructures need to be established that will address the immediate and lasting social support needs of parents, extended family, and communities with deaf children, particularly given the fact that chronic otitis media (with the potential to cause hearing loss) in children is more prevalent in the North than in southern Canada. Although this study dealt with a substantial time period, between initial diagnosis and later reflections on why the deaf youth and later his family left the community, all those involved in the study recognized that the supports, services, and resources were still lacking in the community should another family have a deaf child. The reality is that there may very well be children in the community with significant hearing losses that have yet to be identified as a result of incomplete or inconsistent hearing tests due to lack of qualified professional personnel and gaps in service. During the initial fieldwork for this study, the Stanton Medical Centre, which provides the only audiology services for the Northwest Territories, was actively seeking a second audiologist for their staff. When I returned to the Northwest Territories, more than a year later, the Centre was still (or again – the issue of transitory professional personnel in the North is still an issue) seeking an audiologist for the territories.

Generally speaking, there needs to be a greater awareness of the implications of hearing loss, especially in the aging population, in the North. Preventative care (i.e. health promotion in terms of hearing protection) and systemic attempts to alter the

factors causing hearing loss and deafness (i.e. improve housing conditions) are necessary. Furthermore, deficient government supports, services, and resources regarding issues of hearing loss is the resulting loss of culture, language, and knowledge in First Nations and Inuit communities in the Northwest Territories. In this particular community, there were several adults and elders with varying degrees of hearing loss, which is having a major impact on the level of their involvement in community activities including harvesting trips, events such as community gatherings, and decision-making processes including settlements with government and external natural resource developers. Aboriginal communities are losing contributors to their communities, as is the larger Canadian society, by disengagement due to hearing loss. Without elder involvement in community activities, young people will suffer the consequences in that they will not be able to access the knowledge of the elders, which is already an issue for those that do not speak their original language. By not addressing the issue of adult and elder hearing loss in the form of government health and social service policy, First Nations and Inuit communities are at further risk of in terms of their survival in a Euro-Canadian society.

**Community Recommendations**

During interviews with participants and throughout the formal and informal interactions with community members, several recommendations were provided for improving accessibility to information, resources, services, and supports. I believe Territorial health and education authorities should heed these local recommendations, which offer solutions for dealing with deafness from within this northern community.

The recommendations, though coming from Ehchuse, are not necessarily specific to just that community, instead they are broad enough to apply to all northern communities.

1. Immediate emphasis needs to be placed on developing culturally relevant resources for outside professionals and making them available to each community in the North. Another set of resources that would augment cultural awareness regarding non-Aboriginal perspectives; particularly those grounded in a Euro-Canadian system perspective should be made available to communities. Mutual understanding between communities and the professionals who serve them will no doubt improve relationships and drive out racism. These resources could be developed through partnerships with the health and education authorities and communities. Furthermore, health education and promotion regarding adult hearing loss should be more available to northern communities in each community's first language.

In relation to this recommendation, I would propose that a videotape on deafness be produced. Northern parents, like Sandra, could talk about their experience with a deaf child including a description of how they first suspected their child was deaf, the process they went through in dealing with health practitioners, the decisions they made regarding language and education, and their insights as well as any advice they would give to new parents of deaf children. Grandparents and other extended family members could talk about their experience with a deaf relative. They could describe their level of involvement, ways in which they remain a part of the deaf child's life, and provide suggestions to other families regarding ways to be involved in learning about deafness.

Representatives from the community could recount their experiences regarding their initial reaction to deafness and their subsequent interaction with a deaf member of the community. Community leaders could identify ways to address issues related to access for and acceptance of deaf members in the community. They could also offer counsel on how to lobby for the individual's right to health, education, and social support in the community. Representatives from the health and education authorities as well as Deaf professionals from the social service field could share their knowledge concerning deafness, providing viewers with information about the entire range of issues related to deafness, not just from a medical perspective but also from a cultural perspective. Important sources of written and audio-visual material could be mentioned in the video and parents as well as professionals could comment on the items that have been the most helpful.

Finally, deaf Aboriginal children and adults from the North who have remained in the North as well as those who have left the North could share their experiences and offer their perspectives on the pros and cons of growing up in their respective environments. A videotape of this nature should be produced in the first language of each community as well as in English and ASL. Resources, such as the video proposed here, need to be immediately accessible in the community. This would allow parents and families to spend their time thinking about the issues before coming to an informed, educated decision rather than scrambling to locate resources, support, and services.

2. ASL studies should be available to communities in the Northwest Territories for those interested in learning basic sign communication. In most southern Canadian cities, Deaf people who have training in language instruction are employed by school boards, colleges, and universities to teach ASL to hearing students. A qualified Deaf individual should be contracted as an itinerant teacher by the Northwest Territories Department of Culture, Education, and Employment to provide ASL language instruction for northern communities. Further to this recommendation, I would add that there are abundant resources available regarding teaching and learning ASL for children and adults. Gallaudet University in Washington, DC, the only Deaf university in the world, publishes a wide range of academic and general literature and produces teaching and storytelling videos for those interested in learning ASL.

3. If a family with a deaf child decides to send that child to the local school rather than to a residential school for the Deaf, correspondence courses covering topics on Deaf culture, history, and folklore should be made available through partnerships with residential schools for the Deaf. Regular classroom teachers would be responsible for administering the correspondence course in the mainstream classroom setting and an itinerant teacher of the Deaf should make regular (for example, monthly) classroom visits to deaf students across the North. Mainstream schools with deaf children in southern Canada generally have this type of relationship with a teacher of the Deaf or a coordinator of Deaf services. I would add that teachers in the North with a deaf student in the classroom should receive professional development and ASL (or the preferred

mode of communication) language training prior to and during their time with a deaf student.

4. Training for the entire family offered annually preferably in Yellowknife but alternatively in Edmonton, should be provided. From my own personal experience, I am aware of the fact that in southern cities, one and two week annual courses known as "ASL Immersion" are available for families and friends of deaf children and adults. These ASL Immersion courses are highly successful and include learning and recreational activities appropriate for both adults and children. Similar culturally relevant courses could be developed and held annually in Yellowknife for northern families with deaf children. Local involvement in the development of such courses would be critical to guaranteeing the Aboriginal worldview is included in the content. Establishing partnerships between Deaf instructors and Aboriginal communities would ensure lasting relationships and mutual understanding. Deaf instructors, if they are not Aboriginal, would need cross cultural awareness and sensitivity training.

5. An electronic network should be established that would serve the families of deaf children by providing an outlet for parents' to ask questions and exchange ideas on common issues, thus effectively dealing with the geographical distance between them.

6. A position should be created to coordinate services for the Deaf across the Territories. A Territorial Coordinator of services for the Deaf could effectively deal with the five recommendations cited above. Northern families with deaf children as

well as local and territorial health and education representatives could have input into creating the job description.

7. The community's next recommendation relates to legislation. Disparities in legislation need to be corrected and policies, which have been developed, need to be implemented. New policies need to be created to ensure that medical care is provided to prevent deafness whenever possible and that appropriate medical services are provided for all deaf children and adults with hearing loss.

8. Universal screening for hearing loss or risk of hearing loss in children should take place initially during early childhood, and again upon entering school, as well as throughout the school years.

9. Early interventions provided by medical, educational, and social service personnel who have had cultural sensitivity training should be made available immediately in northern communities.

10. More government funding is necessary to provide the infrastructure needed to support and serve families and communities with deaf children as well as adults and elders with hearing losses.

This thesis could be an impetus for creating linkages among individuals who are deaf or hard of hearing, members of their family, the local community, health care

practitioners, educators, social service personnel, and local, territorial, and federal governments. Clearly Ehchuse's recommendations indicate that there are viable local solutions to local problems and, in this case, the community has concrete ideas about creating culturally specific and relevant supports and resources about deafness.

**Further Recommendations**

It is apparent that integration between service providers and communities requires significant improvement. Granted there are currently a substantial number of service providers in the health and education systems but the system is still experiencing problems. For example, the audiologist noted that she and other service providers including doctors and dentists were consistently frustrated with patients who do not attend their appointments in the community. Home visits by service providers to patients reluctant to making the trip to the clinic might be an effective way for dealing with this problem. In some cases this may be difficult as there may be heavy or large equipment required for testing. In these cases, home visits to the patient could still occur to try to determine what the reluctance is and to try to make the person more comfortable with the idea of coming to the clinic. Not only will the outside service provider achieve his or her goal of seeing the client, the service provider will become more familiar with community members, which will in turn likely reduce the feelings of cultural isolation and misunderstanding. As outside service providers move from cultural ignorance to cultural awareness and sensitivity towards their clients, individual expressions of racism may be dashed and the service providers may, in turn, begin to examine systemic racism within their own institutions. Similarly, training for

communities on the ways in which the healthcare, social service, and education systems are situated within a Euro-Canadian context will also serve to improve relationships within the community between service providers and community members. This process needs to be supported through intervention and training to assist service providers with identifying racism in the system and themselves. Furthermore, those in policy-making and service-providing positions should recognize the enormous capacity of communities to deal with their own issues using local knowledge.

**Deafness in the North: Creating Awareness**

During my stay in Ehchuse, the Canadian Broadcasting Corporation (CBC) aired a short documentary, "Hands Across the Arctic", which highlighted the plight of Inuit parents with deaf children. As noted in the transcript below, the documentary addresses many of the same concerns among the Canadian Inuit population that I was investigating with the Dene people of Ehchuse during the course of this study:

> *Close to a million Canadians... suffer from severe hearing loss. For them, the world is not only silent, but isolating. [There are] some people who feel the isolation most intensely. They live in Canada's far north. This is winter's kingdom: nine months of ice and snow; remote, utterly different from the kind of life most of us understand. In years gone by, deaf Inuit were shipped south to residential schools. Either that, or they were left largely to their own devices with little education and few services. [Generally] nobody else in [the] family [can] sign, so [deaf students go] south to the Schools for the Deaf." But many get homesick and come back home...The change from living in igloos may be contributing to the high incidence of hearing loss in the north. Moving back and forth from the extreme cold outside to overheated houses could be the reason why a quarter of the population suffers from otitis media; an inflammation of the middle ear which can lead to deafness. This is the Inuit's world and few want to leave. But it's been difficult for the deaf to find their place in it. Bringing up a child who can't hear or speak is a*

> *lonely experience. Most of these parents are the only ones with a deaf child in their community. The nearest person who can share their concerns could be a thousand kilometres away.* (Griffiths, 2001)

One of the key findings of this study is that this Dene community's response to having a deaf child has many of the same characteristics as any community that has never before been exposed to deafness. Access to professional support, services, and resources was extremely limited and further exacerbated by geographical distances. Cultural identity plays a significant role in this particular study. The Dene people of Ehchuse continue to carry on a long-established way of life. The language, culture, traditions, values, and beliefs of the Dene have been passed on from generation to generation in this community much the same way it has in most northern communities. Yet, for Aboriginal (and Inuit) individuals in the North who are deaf and do not have access to their original language, and therefore do not have access to the cultural ways of being that are embedded in the language, an incomprehensible remoteness exists. Furthermore, the parents, families, and communities where these deaf individuals live are prevented from passing on their cultural way of being.

**Theoretical Reflections**

In reflecting on the cultural framework for the study, it is anticipated that communities may formulate strategies of their own that will enhance the cultural connection that deaf Aboriginal children have with their original family and community. This cultural imperative has been largely overlooked by the conventional health and education systems. Certainly the data presented in this case study supports the theory of social support with regards to hearing parents of deaf children by

confirming the proposition that social support and professional support are critical in creating a positive outcome for both hearing parents and their deaf children.

**Methodological Reflections**

I attended an Inter-Tribal Deaf Council of North America conference in 1998 prior to beginning my graduate program and shared my research plans with the deaf Aboriginal participants at the conference. There was tremendous support for a study that examined the supports and services available to northern deaf Aboriginal people. I have come to realize, however, that in terms of Ehchuse, I studied an issue of acute interest to Sandra (the mother of Arthur), myself, and other people/organizations external to Ehchuse. The community did recognize the importance of this study but it was also cognizant of the fact that a decade had passed since Arthur had last been in the community and there were now other more pressing community concerns, one of which included hearing loss in adults and elders. However, checks were in place to ensure that this research was useful and relevant to the community. In particular, the Aurora Research Institute's licensing process required for researchers wanting to conduct studies in the North gave me some degree of assurance that the community felt the study was worthwhile. Had the community not lent their support to the study, the license would not have been granted and the research would not have taken place. Additionally, attendance and participation at meetings held with the Chief and Council as well as with the elders' committee during the course of my stay were strong indications that they supported the study.

During my time in Ehchuse, I came to understand the difference between community-based and community-driven research. Having recognized the difference, I had a choice. I could continue with my original study question or I could explore a current community-driven issue regarding hearing loss among adults and elders. I had wanted to have community participation and collaboration from start to finish. However, I realized that several factors created a barrier to achieving full collaboration – factors including geographical distance between myself and the community, time, financial support, and my own limitations as a relatively new researcher. For these reasons, I chose to continue with my original research question and save the experience of conducting a community-driven study for the future at which time I will have developed a greater understanding and skill in utilizing this research methodology. I want to stress however that research on the impacts of hearing loss in adults and elders warrants future attention.

Throughout the study, it has been my foremost concern to protect the well being of participants during the study and any resulting publications or policies that stem from the research. I was aware that I might encounter opposition from community members in my initial negotiation, during the data collection and analysis, and in the final presentation of the results. Understanding that the source of potential opposition would stem from decades of colonization and oppression that Aboriginal people have endured required sensitivity and respect towards Aboriginal people regardless of their willingness or refusal to participate in the project. Having stated this, my experience in Ehchuse was extremely positive and I experienced no outward opposition toward my

doing the study. I was also aware that as an outsider conducting research in a community whose culture is different from my own that I might unknowingly break some cultural rules. I am not fully aware of the cultural rules I may have broken. There were times when I felt uncertain about how to go about requesting interviews and asking questions. I felt unsure as to whether I should participate in certain community activities such as my decision to accept an invitation to join a group of (mostly) young men for their weekly sweats. I concur with Smith (1999) that my approach to Aboriginal cultural values and rules of behaviour were integral to the methodology in that I built these factors into the research, I included them in the research design, and I have reflected on and discussed my experiences as part of the final results of the study. I have contemplated my experience and my decisions regarding my "research methods" and, if I were to conduct a similar study, I do not doubt that I would do so in a similar manner.

**Critical Reflections**

At this juncture, I would like to include my own critical reflections regarding my changing perceptions towards "best practices" for providing services and support to deaf individuals and their families in northern communities as well as my understanding of community-based research.

When I began thinking about deafness in the North, I had a bias towards supporting the argument touted by members of the Deaf community that deaf children should attend residential schools for the Deaf in order to learn the natural language of the

Deaf and to realize their Deaf cultural identity. As I delved further into the study, I discovered the fundamental dilemma. Deaf children from the North who attend residential schools for the Deaf in southern Canada and who live either in dormitories or with host families who know ASL but who do not share the same cultural identity are able to immerse themselves in the Deaf community in southern cities but are no longer able to effectively integrate into their home communities in the North. They are not left with a common language of their families and original communities. They have been stripped of their original cultural identity and they have been robbed of a shared life experience with their families and community members. Yet, many deaf children who go south to residential schools for the deaf have very positive experiences and opportunities that may not have been possible had they remained in their home communities. These children acquire language that is inherently accessible to them and generally gain membership into the Deaf community[26]. The question that remains though, is this: did/do parents have access to the resources, supports, and services that would/will allow them to make informed decisions with reference to sending their child to a school for the deaf and were/are there the supports, services, and resources available to them that would/will allow for their child to remain in a northern community?

Consider the following metaphor. A puzzle represents the relationship I have with the research project and the participants. The participants hold the missing pieces to the puzzle. Part of my research would be to find the people who hold the missing pieces and to help them assemble a picture for Aboriginal families and communities

[26] I have qualified the statement regarding acceptance into the Deaf community because there is no denying that racism, sexism, ageism, homophobia and other acts of oppression exist in the Deaf community, as is the case in the dominant (hearing) society.

who have been affected by deafness. Having assembled the puzzle and analyzed the picture, a second image appears: a caterpillar metamorphosing into a butterfly. This distinct being has two identities over the course of a lifetime. Similarly, a person who is deaf has an original identity that can remain intact after a Deaf identity is assumed. This imagery has helped me draw the conclusion that finding a balance within the two identities should prove more successful in terms of integration in both communities.

**Reporting Back**

Reporting back to communities that have been involved in research, regardless of their level of involvement, is critical. Smith (1999) provides an important perspective on reporting back to communities:

> There are diverse ways of disseminating knowledge and of ensuring that research reaches the people who have helped make it....Reporting back to the people is never ever a one-off exercise or a task that can be signed off on the completion of the written report....Sharing knowledge is also a long-term commitment. It is much easier for researchers to hand out a report or for organizations to distribute pamphlets than to engage in continuing knowledge-sharing processes. (p. 15-16)

I chose to return to Ehchuse to present my thesis to the community. I presented this thesis at a meeting in the Council Chambers. I described my thesis using a poster during my presentation, which I then left with the community. I discussed how the study might be used to the community's advantage, I shared my learning as a student and researcher in Ehchuse, reviewed recommendations from the community, and addressed questions from community residents regarding the research and my thesis. I

donated books on ASL and the Deaf community to the Ehchuse school library. I will provide copies of my thesis to Sandra, the Chief and Council, and at the Council's request, a copy of my thesis will be sent to the Health and Social Services Department of the Government of the Northwest Territories. Returning to the community was an excellent experience and a fantastic opportunity to not only present the thesis but also to re-establish connections with northern friends.

I have done my best to conduct this research in a respectful, collaborative manner. I do not operate under the assumption, having completed the study, that I know what is best for Sandra and other northern parents with deaf children. I acknowledge that there is a great deal that I still do not know and, in fact, a great deal that I have not even conceptualised that I do not know regarding this study. I applaud rather than judge Sandra's decisions and actions as well as the decisions and actions of the community given the scarcity of resources, services, and supports made available to them. I am honoured to have had the opportunity to be a part of sharing Sandra's story with other parents who have found themselves in a similar situation, in desperate need of information, insight, advice, and experience. I realize that my research concerning a Dene community's experience with a deaf child in their midst, regardless of my intensity or prolongation in the community, will never give me full access to their experience. However, as an external researcher investigating a cross cultural study, I have listened to those who have shared to the best of my ability and with deep respect. The community will determine for itself whether I have been a conscientious listener and learner.

Lastly, I would emphasize that I do not speak for the community of Ehchuse. My role has been to bring together and synthesize their voices to the best of my ability in order to document their perspective on supports and services for deaf children and their families in the community in an attempt to overcome the silence of deafness in the North. I offer this thesis to Sandra and the community of Ehchuse to use it as they see fit, perhaps as a tool to seek justice from the Territorial government, which did not carry out its obligation to provide an equal standard of health care and education for all members of the Dene Nation. As a result of this study, Sandra, the extended family, the community, and professionals have the opportunity to reflect on their lived experience, their perceptions towards and knowledge about deafness, their relationships with the community, and their experience with an external researcher.

During the course of my graduate program, I heard from professors and peers that the topic, the method, the methodology, and the researcher change over the course of the study. I would have to agree with that statement in that I have the topic, method, and methodology went through several transformations before I settled down to do this study and I have changed in terms of how I look at community-based/driven research and how critical it is to engage in academic study that is relevant to the people and to involve communities in every stage of the research process. I also want to express the fact that I have not only carried out cross cultural research with the community but I have developed new friendships in the process.

**Conclusion**

Much has been written about the physical impact of chronic otitis media and hearing loss in the North from a medical perspective. However, there has been little written about persons experiencing deafness or hearing loss as a result of this medical condition, especially from a cultural perspective. Given that there continues to be a high incidence in the North of both chronic otitis media and hearing loss in children, documenting Ehchuse's response to having a deaf child in the community has the potential to serve many other northern families and communities who have called for improved services and support – calls that have fallen on deaf ears!

## Bibliography


Abramson, P. (1992). A Case for Case Studies: An Immigrant's Journal. Newbury Park, CA: Sage Publications, Inc.

Apuzzo, M., & Yoshinaga-Itano, C. (1995). Early identification of infants with significant hearing loss and the Minnesota Child Development Inventory. Seminars in Hearing, 16(2), 124-139.

Armitage, A. (1995). Comparing the Policy of Aboriginal Assimilation: Australia, Canada and New Zealand. Vancouver: UBC Press.

Association of Canadian Universities for Northern Studies. (1982) Ethical Principles for the Conduct of Research in the North [Web Page]. URL: http://aix1.uottawa.ca/associations/aucen-acuns/en/n_res_02.html [1999, March 12].

Ayim, M. (1997). Crimes against the Deaf: The politics of ableism. Canadian Journal of Education, 22(3), 330-335.

Babbie, E. (1992). The Practice of Social Research (6th Ed. ed.). Belmont: Wadsworth Publishing.

Baker, C., & Battison, R. (1980). Sign Language and the Deaf Community: Essays in Honor of William C. Stokoe. Silver Spring, MD: National Association of the Deaf.

Baxter, J. (1999). Otitis media in Inuit children in the Eastern Canadian Arctic-an overview-1968 to date
Source: International journal of pediatric. International Journal of Pediatric Otorhinolaryngology, 49(1), 165-169.

Baxter, J. (1990). An overview of twenty years of observation concerning etiology, prevalence, and evolution of otitis media and hearing loss among the Inuit in the Eastern Arctic. Circumpolar Health 90: Proceedings of the 8th International Congress on Circumpolar Health (pp. 616-619). Winnipeg, MB: University of Manitoba Press for the Canadian Society for Circumpolar Health.

Best, J., & Kahn, J. (1998). Research in Education (8 ed.). Needham Heights, MA: Allyn & Bacon.

Bjerregaard, P., & Young, T. (1998). The Circumpolar Inuit: Health of a Population in Transition. Munksgaard, Copenhagen: Special-Trykkeriet Viborg a-s.

Bodner-Johnson, B. (1986). The family environment and the achievement of deaf students: A discriminant analysis. Exceptional Children, 52, 443-449.

Bradley, R., Rock, S., Whiteside, L., Caldwell, B., & Brisby, J. Dimensions of parenting in families having children with disabilities. Exceptionality, 1991(2).

Brand, H., & Coetzer, M. (1994). Parental response to their child's hearing impairment. Psychological Reports, 75(3), 1363-1368.

Brown, L. (1982). Ambiguities in participatory research. B. Hall, A. Gillette, & R. Tandon (Eds), Creating Knowledge: A Monopoly? (pp. 203-209). New Delhi: Society for Participatory Research in Asia.

Brown, L. (1985). People-centered development and participatory research. Harvard Educational Review, 55, 69-75.

Bryar, R. (1999). An examination of case study research. Nurse Researcher, 7(2), 61-78.

Canadian Council for Refugees. (1996) Anti-Racism Policy [Web Page]. URL http://www.web.net/~ccr/arpolicy.htm [1906, January 28].

Castleden, D. (1992). Collaborative Community Research and Change in an Aboriginal Health System: A Case Study of Participatory Education and Inquiry for Introducing Systems Change in a First Nation in Northern Canada. Unpublished doctoral dissertation, University of Massachusetts, Amherst, MA.

Castleden, H. (Unpublished paper prepared for the Associate Director of Circumpolar Health, Canadian Circumpolar Institute, University of Alberta). The State of Health in the Circumpolar North.

Christensen, K. (2000). Deaf Plus: A Multicultural Perspective. San Diego,CA: DawnSignPress.

Cody, I. E. (1970). Indian Talk: Hand Signals of the American Indians. London: New English Library.

Cohen, L. (1995). Train Go Sorry: Inside a Deaf World. New York: Vintage Books.

Cokely, D., & Baerk C. (1980). American Sign Language: A Student Text. Silver Spring: T.J. Publishers.

Colorado, P. (1988). Bridging Native and Western science. Convergence, XXI(2/3), 49-64.

Courtois, J. (1990). Audiological rehabilitation of Greenlandic patients with hearing loss due to Otitis Media. Circumpolar Health 90: Proceedings of the 8th International Congress on Circumpolar Health (pp. 639-641). Winnipeg, MB: University of Manitoba Press for the Canadian Society for Circumpolar Health.

Crago, M., Dufour, R., Therien, F., & & Neinhyus, T. (1991). An international working group on otitis and hearing with Aborigional populations.

Crago, M., & Tremblay, C. (1990). Obstacles, challenges, and solutions: Evolution in audiological service delivery to the hearing-impaired Inuit of northern Quebec. Circumpolar Health 90: Proceedings of the 8th International Congress on Circumpolar Health (pp. 633-638). Winnipeg, MB: University of Manitoba Press for the Canadian Society for Circumpolar Health.

DeCourtney, C. (1998). Alaska Native community assessment" Health care services, knowledge of health issues, and health education. Circumpolar Health 96: Proceedings of the Tenth International Congress on Circumpolar Health (pp. 656-661). Anchorage, Alaska: American Society for Circumpolar Health.

Desselle, D. (1994). Self-esteem, family climate and communicative patterns in relation to deafness. American Annals of the Deaf, 139(3), 322-328.

Dufour, R. (1990). The search for the etiology of Otitis Media: Results obtained with an application of the system theory. Circumpolar Health 90: Proceedings of the 8th International Congress on Circumpolar Health (pp. 626-629). Winnipeg, MB: University of Manitoba Press for the Canadian Society for Circumpolar Health.

Dyson, L. (1993). Response to the presence of a child with disabilities: Parental stress and family functioning over time. American Journal on Mental Retardation, 98(2), 207-218.

Eleweke, J., & Rodda, M. (2000). Factors contributing to parents' selection of a communication mode to use with their deaf children. American Annals of the Deaf, 145(No. 4), 375-383.

Elssman, S., Matkin, N., & Sabo, M. (1987). Early identification of congenital sensorineural hearing impairment. The Hearing Journal, 9, 13-17.

Frazier-Maiwald, V., & Williams, L. (1999). Keys to Raising a Deaf Child. Hauppauge, NY: Barron's Educational Series, Inc.

Freire, P. (1970). Pedagogy of the Oppressed. New York: Continuum.

Friedel, T. (1999). The role of Aboriginal parents in public education: Barriers to change in an urban setting. Canadian Journal of Native Education, 23(No.2), 139-158.

Fronval, G., & Dubois, D. (1985). Indian Signals and Sign Language. New York: Bonanza Books.

Gallaudet, T. (1997). On the natural language of signs; and its value and uses in the instruction of the deaf and dumb. American Annals of the Deaf, 142(3), 79-93.

Gannon, J. (1987). Deafness: A plate glass prison? Canadian Journal of the Deaf, 1(1), 5-12.

Garvin, T., & Eyles, J. (2001). Public health responses for skin cancer prevention: The policy framing of Sun Safety in Australia, Canada and England. Social Science and Medicine, 3185, 1-15.

Geertz, C. (1973). The Interpretation of Cultures. New York: Basic Books.

Georgetti, K. (President). (1997) The International Day for the Elimination of Racial Discrimination [Web Page]. URL http://www.clc-ctc.ca/human-rights/anti-racism-stmt-21mar97.html [1906, January 28].

Goetzinger, C., & LeCompte, M. (1984). Ethnography an Qualitative Design in Educational Research. New York: Academy.

Government of Canada. (1996) Census of Canada: Statistics Canada [Web Page]. URL http://www.statscan.ca/english/census96/list.htm [2001, June 23].

(1996). Hull, PQ: Minister of Public Works and Government Services Canada.

Greeenberg, M. (1983). Family stress and child competence: The effects of early intervention for families with deaf infants. American Annals of the Deaf, 128, 407-417.

Gregory, S., Bishop, J., & Shelton, L. (1995). Deaf Young People and Their Families: Developing Understanding. New York: Cambridge University Press.

Griffiths, A. (Reporter). (Hands Across the Arctic [Web Page]. URL http://cbc/national/magazine/deaf/index.html [2001, April 17].

Groce, N. (1985). Everyone Here Spoke Sign Language: Hereditary Deafness on Martha's Vineyard. Cambridge, MA: Harvard University Press.

Haig-Brown, C. (1988). Resistance and Renewal: Surviving the Indian Residential School. Vancouver: Arsenal Pulp Press.

Harrison, M., & Roush, J. (1996). The age of suspicion, identification and intervention for infants and young children with hearing loss: A national survey. Ear and Hearing, 17(1), 55-62.

Harrison, M., & Roush, J. (1996). Age of suspicion, identification, and intervention for infants and young children with hearing loss: National study. Ear and Hearing, 17(1), 55-62.

Henggeler, S., Watson, M., Whelan, P., & Malone, C. (1990). The adaptation of hearing parents of hearing-impaired youth. American Annals of the Deaf, 135(3), 211-216.

Hermes, M. (1998). Research methods as a situated response: Towards a First Nations' methodology. International Journal of Qualitative Studies in Education. 11(1): 155-168.

Hintermair, M. (2000). Hearing impairment, social networks, and coping: The need for families with hearing-impaired children to relate to other families and to hearing-impaired adults. American Annals of the Deaf, 145(No. 1), 41-53.

Hobfoll, S., & Lerman, M. (1988). Personal relationships, personal attributes, and stress resistance: Mothers' reactions to their child's illness. Journal of Community Psychology, 16, 565-589.

Hyde, M., & Power, D. (1992). The receptive communication abilities of deaf children: Studies under oral, manual, and combined methods. American Annals of the Deaf, 137(5), 389-398.

Jette, M. (1998). A health profile of the Inuit of Nunavik: Report of the Sante Quebec Health Survey (1992). Circumpolar Health 96: Proceedings of the Tenth International Congress on Circumpolar Health (pp. 630-635). Anchorage, Alaska: American Society for Circumpolar Health.

Kaiser, S. (1990) Issues of Culture and Oppression in Organizations [Web Page]. URL http://www.bizgrowth.com/culture.html [2001, June 14].

Keupp, H., & Rohrle, B. (1985). Soziale Netzwerke. Frankfurt, Germany: Campus.

Kramer, A., & McCullough, D. (1998). The Prevalence of Otitis Media with Effusion among Inuit Children. Circumpolar Health 96: Proceedings of the Tenth International Congress on Circumpolar Health (pp. 265-267). Anchorage, Alaska: American Society for Circumpolar Health.

La Fromboise, T., & Plake, B. (1983). Toward meeting the research needs of American Indians. Harvard Educational Review, 53(1), 45-51.

Lane, H. (1999). The Mask of Benevolence: Disabling the Deaf Community (2 ed.). San Diego: DawnSignPress.

Lane, H., Hoffmeister, R., & Bahan, B. (1996). A Journey into the Deaf-World. San Diego, CA: DawnSign Press.

Lederberg, A. (1993). The impacts of deafness on mother-child and peer relationships. M. Marschark, & D. Clark (Eds), Psychological Perspectives on Deafness (pp. 93-119). Hillsdale, NJ: Erlbaum.

Lewin, K. (1946). Action research and minority problems. The Journal of Social Issues, 2, 34-46.

Lincoln, Y., & Guba, E. (1985). Naturalistic Inquiry. Beverly Hills, CA: Sage.

Livingstone, S. (1997). Rethinking the Education of Deaf Students: Theory and Practice from a Teacher's Perspective. Portsmouth, NH: Heinemann.

Loury, M. (MD). (1905) Discovery Health Diseases and Conditions: Chronic Otitis Media [Web Page]. URL: http://health.discovery.com/diseasesandcond/encyclopedia/2335.html [1904, January 14].

Luetke-Stahlman, B. (1998). Language Issues in Deaf Education. Hillsboro, OR: Butte Press.

Luetke-Stahlman, B., & Milburn, W. (1996). A History of Seeing Essential English (SEE I). American Annals of the Deaf, 141(1), 29-33.

Lynas, W. (1994). Communication Options in the Education of Deaf Children. London: Whurr.

MacTurk, R., Meadow-Orlan, K., Sanford-Koester, L., & Spencer, P. (1993). Social support, motivation, language, and interaction: A longitudinal study of mothers and deaf infants. American Annals of the Deaf, 138, 19-25.

Magnuson, M., & Hergils, L. (1999). The parents' view on hearing screening in newborns: Feelings, thoughts, and opinions on OAE screening. Scandinavian Audiology , 28(1), 47-56.

Magnusson, M. (2000). Infants with congenital deafness: On the importance of early sign language acquisition. American Annals of the Deaf, 145(No. 1), 6-14.

Maguire, P. (1987). Doing Participatory Research: A Feminist Approach. Amherst, MA: Center for International Education, University of Massachusetts.

Mallery, G. (1972). Sign Language Among North American Indians Compared with that Among Other Peoples and Deaf-Mutes. The Hague: Mouton and Co.

Mapp, I., & Hudson, R. (1997). Stress and coping among African American and Hispanic parents of deaf children. American Annals of the Deaf, 142, 48-56.

Marshcahrk, M. (1997). Raising and Educating a Deaf Child. New York: Oxford University Press.

Martin, B., & Macdonald, S. (1998). The management of ear disease: Guidelines for Aboriginal health care programs. Circumpolar Health 96: Proceedings of the Tenth International Congress on Circumpolar Health (pp. 268-275). Anchorage, Alaska: American Society for Circumpolar Health.

Mason, D., & Ewoldt, C. (1996). Whole language and deaf bilingual-bicultural education naturally! American Annals of the Deaf, 141(4), 293-298.

Meadow-Orlans, K. (1995). Sources of stress for mothers and fathers of deaf and hard of hearing infants. American Annals of the Deaf, 140, 352-357.

Meadow-Orlans, K. (1994). Stress, support, and deafness: Perceptions of infants' mothers and fathers. Journal of Early Intervention, 18, 91-102.

Meadow-Orlans, K., Mertens, D., Sass-Lehrer, M., & Scott-Olson, K. (1997). Support services for parents and their children who are deaf or hard of hearing: A national survey. American Annals of the Deaf, 142(4), 278-293.

Meiher P, & Pugh E . (1986). The case study: A viable approach to clinical research. Research in Nursing and Health, 9, 195-202.

Merriam, S. (1988). Case Study Research in Education: A Qualitative Approach. San Francisco: Josey Bass Publishers.

Mertens, D., Sass-Lehrer, M., & Scott-Olson, K. (2000). Sensitivity in the family-professional relationship: Parental experiences in families with young deaf and hard of hearing children. C. E. &. M. M. P. Spencer (Eds), The Deaf Child in the Family and at School: Essays in Honor of Kathryn P. Meadow-Orlans (pp. 133-150). Mahway, NJ: Lawrence Erlbaum Associates Publishers.

Minnes, P., McShane, J., Forkes, S., & Green, S. (1989). Coping resources of parents of developmentally handicapped children living in rural communities. Australia and New Zealand Journal of Developmental Disabilities, 15(2), 109-118.

Moore, J. (1990). Delivery of audiologic service and prevalence of hearing loss in the western Canadian Arctic. Circumpolar Health 90: Proceedings of the 8th International Congress on Circumpolar Health (pp. 630-632). Winnipeg, MB: University of Manitoba Press for the Canadian Society for Circumpolar Health.

Moore, J. (1994). Environmental and Health Factors Affecting Conductive Hearing Loss in Inuit Children. Unpublished doctoral dissertation, University of Illinois at Urbana-Champaign, University of Illinois Press.

Moores, D. (1996). Educating the Deaf: Psychology, Principles, and Practices (4 ed.). Boston: Houghton Mifflin.

Morgan-Redshaw, M., Wilgosh, L., & Bibby, M. (1990). The parental experiences of mothers of adolescents with hearing impairments. American Annals of the Deaf, 135, 293-298.

Morton, D. (2000). Beyond parent education: The impact of extended family dynamics in deaf education. American Annals of the Deaf, 145(No.4), 359-365.

Nichols, M. (1994). Family communication and the right to sign. Perspectives in Education and Deafness, 12(1), 18-21.

Niclasen, B. (1998). Disease pattern in children living in the Arctic: Visits to a general practitioner by 0- to 14- year-old children living in Nuuk, Greenland. Circumpolar Health 96: Proceedings of the Tenth International Congress on Circumpolar Health (pp. 141-147). Anchorage, Alaska: American Society for Circumpolar Health.

Nybo, W., Scherman, A., & Freeman, P. (1998). Grandparents' role in family systems with a deaf child. American Annals of the Deaf, 143(260-267).

O'Neil, J., Reading, J., Bartlett, J., Young, T., & Kaufert, J. (1999). Integrating a Focus on Aboriginal Health Research in the Development of the Canadian Institutes of Health Research: A Concept Paper. Winnipeg: Department of Community Health Sciences, University of Manitoba.

Odgen, P. (1997). The Silent Garden: Raising Your Deaf Child. Washington, DC: Gallaudet University Press.

Padden, C., & Humphries, T. (1988). Deaf in America: Voices from a Culture. Cambridge, MA: Harvard University Press.

Patton, M. (1990). Qualitative Evaluation and Research Methods (2nd Ed). Newbury Park: Sage Publications.

Pegram, A. (1999). What is case study research? Nurse Researcher, 7(2), 5-16.

Platt, J. (1988). What can case studies do. Studies in Qualitative Methodology, 1, 1-23.

Pletsch, C. (1985). Subjectivity and biography. S. Baron & C. Pletsch (Eds), Introspection in biography . Hillsdale, NJ: Analytic Press.

Poon, B. (1999). Parental reactions to deafness in children: A grounded theory investigation (An unpublished thesis). Unpublished doctoral dissertation, University of Alberta, Edmonton, AB.

Power, D., Wood, D., Wood, H., & MacDougall, J. (1990). Maternal control over conversations with hearing and deaf infants and young children. First Language, 10, 19-35.

Queen, T. (MD). (Virginia Ear Nose Throat and Allergy [Web Page]. URL http://www.vaentallergy.com [2001, April 13].

Reagan, T. (1989). Nineteenth-century conceptions of deafness: Implications for contemporary education practice. Education Theory, 39(1), 39-46.

Reason, P. (1988). Human Inquiry in Action. London: Sage Publications.

Reinholtz, M. (1986). Knowledge of Five Types of Educational Professionals Regarding Otitis Media and Related Behaviors. Unpublished doctoral dissertation, Northern Arizona University, Northern Arizona University Press.

Rogers, C. (1961). On Becoming a Person. Boston: Houghton Mifflin.

Rogers, C. (1980). A Way of Being. Boston: Houghton Mifflin.

Royal Commission on Aboriginal Peoples. (1996). Renewal: A Twenty-year Commitment (vol.5). Ottawa: Government of Canada.

Runyan, W. (1982). Life histories and psychobiography. New York: Oxford University Press.

Sacks, O. (1989). Seeing Voices: A Journey into the World of the Deaf. New York: Harper Perennial.

Schlesinger, H., & Meadow, K. (1972). Sound and Sign: Childhood Deafness and Mental Health. Berkeley, Los Angeles, London: University of California Press.

Segal, M. (1985). An interview study with mothers of handicapped children to identify both positive and negative experiences that influence their ability to cope. Paper presented at the meeting of the National Centre for Infants' Programs Washington, DC.

Simons, R. (1987). After the Tears: Parents Talk About Raising a Child with a Disability. New York: Harcourt Brace Jovanovich, Publishers.

Skutnabb-Kangas . (1984). Bilingualism or Not The Education of Minorities. Clevedon, England: Multi-Lingual Matters.

Smith, L. (1999). Decolonizing Methodologies: Research and Indigenous Peoples. London: Zed Books.

Smith, L. (no date provided). Kaupapa Maori Methodology: The Researched 'Research Back'. University of British Columbia.

Stake, R. (1994). Case studies. N. Denzin, & Y. Lincoln (Eds), Handbook of Qualitative Research (pp. 236-247). Thousand Oaks, CA: Sage.

Statistics Canada (Government of Canada). (1996) Census 1996: Population by Aboriginal Group [Web Page]. URL http://www.statscan.ca/english/Pgdb/People/Population/demo39a.htm [2001, June 24].

Stedt, J., & Moores, D. (1990). Manual codes on English and American Sign Language. H. Bornstein (Ed.), Manual Communication: Implications for Education (pp. 1-20). Washington: Gallaudet University Press.

Steinberg, A. (2000). Autobiographical narrative on growing up deaf. C. E. &. M. M. P. Spencer (Eds), The Deaf Child in the Family and at School: Essays in Honor of Kathryn P. Meadow-Orlans. (pp. 93-108). Mahwah, NJ: Lawrence Erlbaum Steinberg, Lawrence Erlbaum Associates Publishers.

Tandon, R. (1981). Participatory research in the empowerment of people. Convergence, 14, 20-27.

Tandon, R. (1988). Social transformation and participatory research. Convergence, 21, 5-18.

Taylor, D., Crago, M., & McAlpine, L. (1993). Education in Aboriginal communities: Dilemmas around empowerment. Canadian Journal of Native Education, 20, 176-183.

Torbert, W. (1981). Why educational research has been so uneducational: The case for a new model of social science based on collaborative inquiry. R. Reason, & J. Rowan (Eds), Human Inquiry (pp. 141-151). Chichester, UK: John Wiley.

Trimble, J. (1977). The sojourner in the American Indian community: Methodological issues and concerns. Journal of Social Issues, 33, 159-174.

Umiker-Sebeok, J., & Sebeok, T. (1978). Aboriginal Sign Lanugages of the Americas and Australia. New York: Plenum Press.

Vaccari, C., & Marschark, M. (1997). Communication between parents and deaf children: Implications for social-emotional development. Journal of Child Psychology and Psychiatry, 38(7), 793-801.

Valli, C., & Ceil, L. (1995). Linguistics of American Sign Language: An Introduction (2nd ed.). Washington: Gallaudet University Press.

Vanfossen, B. (1986). Sex differences in depression: The role of spouse support. S. Hobfoll (Ed), Stress, Social Support, and Women (pp. 69-84). Washington, DC: Hemisphere.

Waldram, J., Herring, D., & Young, T. (1995). Aboriginal Health in Canada: Historical, Cultural, and Epidemiological Perspectives. Toronto: University of Toronto Press.

Watkin, P., Baldwin, M., Dixon, R., & Beckman, A. (1998). Maternal anxiety and attitudes to universal neonatal hearing screening. British Journal of Audiology, 32(1), 27-37.

Wilcoxon, A. (1987). Grandparents and grandchildren: An often neglected relationship between significant others. Journal of Counseling and Development, 65, 289-290.

Winefiled, R. (1987). Never the Twain Shall Meet: Bell, Gaullaudet, and the Communication Debate. Washington, DC: Gallaudet University Press.

Wood, D., Wood, H., Griffiths, A., & Howarth, I. (1986). Teaching and Talking with Deaf Children. Chichester and New York: John Wiley & Sons.

Woodward, J. (1982). How You Gonna Get to Heaven if You Can't Talk to Jesus: On Depathologizing Deafness. Silver Spring, MD: T.J. Publishers.

Yin R. (1994). Case Study Research. New York: Sage Publications, Inc.

Young, T. (1988). Health Care and Cultural Change: The Indian Experience in the Central Subarctic. Toronto: University of Toronto Press.

Zurita, R. (1992). A Case-Control Study of Chronic Otitis Media and Acculturation Among the Yukon-Kuskokwim Delta Eskimos. Unpublished doctoral dissertation, The University of Michigan, The University of Michigan Press.

## Appendix 1

*ASL:*
The North American Deaf community uses American Sign Language (ASL). ASL is a complete language with its own distinct grammatical rules and syntax. Contrary to popular belief, ASL is not a universally signed language nor does it follow English word order.

*MCE:*
Manually Coded English (MCE) includes a variety of different sign systems that are based on the English language including Seeing Essential English (SEE 1), Signing Exact English (SEE 2), and Conceptually Accurate Signed English (CASE). They are not true languages. Instead, they are systems that are used to present manual representations of grammatically correct English.

*PSE:*
Pidgin Signed English (PSE) combines ASL signs and concepts with English word order. PSE does not provide a language model for either ASL or English.

*Cued Speech:*
Cued speech is an oral method that uses hand cues around the mouth to identify the sounds that are being produced. The cues do not denote any concepts or words.

*Oral/Aural Approach:*
This refers to methods that rely on auditory training and speech training to develop oral language. Training individuals to lip-read or speech-read is a component of this methodology. Reliance on residual hearing is encouraged and those who practice these methods discourage the use of sign language.

*Bilingual/Bicultural Approach:*
ASL is the primary language that is taught and used to provide a strong language foundation. English is later acquired using ASL as the language of instruction and supplemented with English in the written form. Having mastery in one language facilitates the acquisition of a second language. The deaf child then has the opportunity of knowing two languages and the ability to live in both cultures.

*Total Communication Approach*:
This approach supports the use of all methods for learning language including ASL, gestures, written language, use of auditory and verbal skills. Consistent meaning of this approach is lacking though generally those who adhere to this approach use signed English and spoken English simultaneously.

## Appendix 1

| Pros for Oral/Aural: |
|---|
| • Emphasis is on developing speech to function in a hearing world.<br>• Use of residual hearing and the latest technology available is encouraged.<br>• Parents do not have to change their way of communication. |
| **Cons for Oral/Aural:** |
| • Limited exposure to other deaf children and adults.<br>• Deafness is seen as a handicapping condition, a medical problem to be fixed with technology.<br>• Language learning may be compromised because children miss valuable information using listening alone. |
| **Pros for Bilingual/Bicultural:** |
| • Hearing families are welcomed and have access to the Deaf community, culture, and language. Children and parents have access to Deaf role models.<br>• Self-esteem of the Deaf child is of primary consideration. Deafness is not seen as a disability but as a cultural/linguistic difference that deserves respect.<br>• ASL establishes a strong primary language system and English is supported through print. |
| **Cons for Bilingual/Bicultural:** |
| • ASL is a priority in the classroom. However, there is no continual access to spoken English. Speech and listening are practiced on an individual basis.<br>• Hearing parents may have a difficult time becoming fluent ASL signers and as a result are not good ASL role models for their children.<br>• "Fix-it" technologies such as cochlear implants are negatively viewed. |
| **Pros for Total Communication:** |
| • Hearing parents are able to transmit their native language, English, through the use of signs to their child. It may be easier to learn a sign system because signs match spoken English words.<br>• Information is available to children in both sign and speech. Parents are encouraged to take advantage of all the technology available.<br>• Children have the tools necessary to participate in both the hearing and deaf cultures. Manually Coded English is learned first and helps children to learn to read English. |
| **Cons for Total Communication:** |
| • The Deaf community views Manually Coded English as an interference on ASL, the language of the Deaf.<br>• Many programs lack consistency in sign use. Teachers may have a range of skill level from beginning to fluent. Different systems may also be used in classes within the same school.<br>• It is difficult to place equal emphasis simultaneously on both signs and speech. It is difficult to sign everything you say and many words may be omitted. |

Source: Frazier-Maiwald & Williams, 1999, pp.94-97.

## Appendix 2

### Case Study Research

1. "It is of the essence of case study method that it entails the collection of intensive data about all aspects of the individual case, including those which may be unique, and that it treats the case holistically rather than isolating variables. It aims to make behaviour intelligible by providing data about personal experiences and their meaning, and taking into account the history and social context of the case. It follows that special importance is attached to the individual's own version of events, which means that the researcher's perceptions should not be imposed and that as far as possible data should be collected in the subject's own words. No particular mode of analysis is implied, but it should be non-quantitative; generalization may be of interest, and if it is, a typological strategy is appropriate' (Platt 1992).

2. '…research projects which attempt to explain wholistically the dynamics of a certain historical period of a particular social unit' (Stoecker 1991).

3. 'The case study is a research strategy that may involve qualitative and/or quantitative technologies, but that is always orientated toward understanding for some purpose a One, whether that one is a singular entity, such as a person, or an aggregate or spatio-temporally defined entity, such as a family, organization, cultural group, or event' (Sandelowksi 1996).

4. '…is an empirical inquiry that: investigates a contemporary phenomenon within its real-life context when the boundaries between phenomenon and context are not clearly evident and in which multiple sources of evidence are used' (Yin 1992).

5. 'Case studies take as their subject one or more selected examples of a social entity – such as communities, social groups, organizations, events, life histories, families, work teams, roles or relationships – that are studied using a variety of data collection techniques. The criteria which inform the selection of the case, or cases, or a study determine its location on the continuum between the descriptive report of an illustrative example and the rigorous test of a well-defined thesis. Using a variety of data collection techniques and methods allows a more rounded, holistic study than with any other design' (Hakim, 1987).

6. 'A case study is an empirical inquiry that
   - investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident,
   - copes with the technically distinctive situation in which there will be many more variables than data points, and as one result,
   - relies on multiple sources of evidence, with data needing to converge in

## Appendix 2

- a triangulating fashion, and as a result,
- benefits from the prior development of theoretical propositions to guide data collection and analysis' (Yin 1994).

7. 'The case study design involves an intensive exploration of a single unit of study: a person, family, group, community, or institution or a very small number of subjects who are examined intensively. Although the number of subjects tends to be small the number of variables is usually large. In fact it is important to examine all variables that might have an impact on the situation being studied (Burns and Groves 1997).

Definitions of case study research taken from: Bryar, 1999, pp.61-78.

## Appendix 3

### DESCRIPTION OF PROJECT AND PROCEDURES FOR OBSERVING ETHICAL GUIDELINES

**Short Title**: Deafness in northern Indigenous Communities: Parent Perspectives on Supports and Resources

**Applicant**: Heather Castleden

**Purpose**: This research project is intended to serve a multitude of people living over a wide geographic area of northern Canada belonging to diverse cultural groups who are inextricably linked to one another by a singular issue - deafness. I will investigate whether Aboriginal families and communities have the support and access to information they need to address the educational issues that are fundamental to raising a child who is deaf. I intend to determine the extent of availability, accessibility, quality, and distribution of educational resources on deafness, and level of user satisfaction, within the Aboriginal population in the North. I intend to include Aboriginal participants' perspectives regarding positive and negative experiences and their recommendations for more effectively addressing educational issues regarding deafness.

**Methodology**: This research will be community-based, developed with input provided by pertinent stakeholders. I intend to employ a qualitative approach to the research using critical ethnography and situated response. I will collect data through personal, in-depth interviews using culturally appropriate interviewing techniques. I will attempt to bring together the different perspectives of people affected by deafness in different ways in terms of how their needs can most effectively be met. I will also conduct a review of the available literature on deafness. I will pay particular attention to any documentation regarding resources for and about deafness as well as federal and territorial health and education policies on deafness in the northern Aboriginal population.

**Nature of Involvement of Human Participants**: Potential research participants include individuals who are deaf, their families, community members and leaders, health care professionals (family physicians, ear, nose and throat (ENT) specialists, audiologists, speech and language therapists), educators, educational support staff, social service providers (social workers, child and family service workers, rehabilitation counselors, human service workers), and interpreters.

**Are underage or "captive" participants involved?** **Yes** ✓ **No**
**If "yes" provide details (attach any consent forms used)**
There is a possibility that interviews may be conducted with underage participants. I have attached a consent form (Appendix B) that will be used if the need arises.

## Appendix 3

**Please describe clearly the specific procedures for observing the University of Alberta ethical guidelines for research involving human participants.**

**1. Explaining purpose and nature of research to participants:**
On the consent form (see Appendix A), I will state the purpose and nature of the research to participants. I will also read it with participants and explain the purpose verbally allowing for questions and clarification. When I explain the purpose of the research to participants who are Deaf, I will use American Sign Language to communicate.

**2. Obtaining informed consent of participants:**
I will explain the purpose and content of the consent form to each participant. I will explain the rights of the participants according to Guideline 6 in the University Standards for the Protection of Human Research Participants. Where participants are underage, I will also make these explanations to their parents or guardians (see Appendix B).

**3. Providing for exercising right to opt out:**
I will explain to the prospective participants that they are not obligated to take part in the study. In addition, I will explain that if they decide they would like to participate they can, at any point in the project, withdraw without penalty and all information they have contributed prior to that time will be removed from the thesis.

**4. Addressing anonymity and confidentiality issues:**
I will stress anonymity and confidentiality to individuals and communities. If participants prefer that their names be printed, I will do so with their written permission only. In order to conceal identity, I will use pseudonyms for names of people and places. I anticipate using audiotapes during interviews with people who hear and videotapes during interviews with people who are deaf. I will transcribe any interview conducted in American Sign Language (ASL) into English. The videotapes will be treated in the same manner as audiotapes in terms of confidentiality, ie. all tapes will be kept in a locked case during the study and destroyed once the study has been completed.

**5. Avoiding threat or harm to participants or to others:**
Every effort will be made to fully protect the welfare and dignity of participants during the project and as a result of any recommendations that stem from the project. I will provide copies of transcripts to the participants for approval before analyzing the results. I will present an analysis of the results of the research and develop a set of recommendations based on consultation with the appropriate stakeholders regarding ways to meet the educational needs to cope with deafness in northern Aboriginal communities. As a member of the University community, I subscribe to the values that protect the dignity and well being of participants involved in my research project.

**6. Other procedures relevant to observing ethical guidelines not described above:**
N/A

## Appendix 3

### CONSENT FORM

I, _____, agree to participate in the research project titled "Deafness in northern Indigenous communities: Parent Perspectives on Supports and Resources." The purpose of this project is to investigate whether Aboriginal families and communities have the support and access to information that they need to address the educational issues that are fundamental to raising a child who is deaf.

The study is being conducted by Heather Castleden, a graduate student in the Adult and Higher Education Program, in the Department of Educational Policy Studies, Faculty of Education at the University of Alberta in partial fulfillment of the requirements for a Master of Education degree. Heather Castleden is conducting this study under the guidance of Drs Peggy and Stan Wilson of the University of Alberta. The Ethics Review Committee of the Faculty of Education at the University of Alberta has approved the study.

The project is intended to serve a multitude of people living over a wide geographic area of northern Canada belonging to diverse cultural groups who are inextricably linked to one another by a singular issue - deafness. With participant involvement, Heather intends to determine the extent of availability, accessibility, quality, and distribution of educational resources on deafness, and level of user satisfaction, within the Aboriginal population in the North. Heather will include Aboriginal participants' perspectives regarding positive and negative experiences and their recommendations for more effectively addressing educational issues regarding deafness.

I understand that my participation involves being interviewed by Heather on one or more occasions. Heather will ask me questions about my experience with educational issues regarding deafness. She may take notes and may use an audiotape or videotape during the interview. My comments may be used as part of her thesis. I have been assured that all information will be kept confidential and that my identity will not be revealed unless I give my written permission.

My participation in this study is voluntary and I may withdraw from the study at any time by simply telling Heather. I may refuse to answer any questions. I will receive answers to my questions about the study at any time. I will receive a copy of any transcripts for approval prior to analysis and I can make changes when misunderstanding has occurred. I will receive a copy of the thesis upon completion.

I understand that I can contact Heather Castleden at (780) 460 2258 at any time regarding this project. I can also contact Heather Castleden's advisors, Drs Peggy and Stan Wilson at the University of Alberta (780) 492 7625 regarding any concerns I have about Heather Castleden or the project.

I agree to participate in this project.

Interviewee: _____ Date: _____

Interviewer: _____ Date: _____

Please circle:

I do / do not wish my identity to be revealed in this thesis.

## Appendix 3

### CONSENT FORM FOR UNDERAGE PARTICIPANTS

I, _____ , agree to participate in the research project titled "Deafness in northern Indigenous communities: Parent Perspectives on Supports and Resources." The purpose of this project is to investigate whether Aboriginal families and communities have the support and access to information that they need to address the educational issues that are fundamental to raising a child who is deaf.

The study is being conducted by Heather Castleden, a graduate student in the Adult and Higher Education Program, in the Department of Educational Policy Studies, Faculty of Education at the University of Alberta in partial fulfillment of the requirements for a Master of Education degree. Heather Castleden is conducting this study under the guidance of Drs Peggy and Stan Wilson of the University of Alberta. The Ethics Review Committee of the Faculty of Education at the University of Alberta has approved the study.

The project is intended to serve a multitude of people living over a wide geographic area of northern Canada belonging to diverse cultural groups who are inextricably linked to one another by a singular issue - deafness. With participant involvement, Heather intends to determine the extent of availability, accessibility, quality, and distribution of educational resources on deafness, and level of user satisfaction, within the Aboriginal population in the North. Heather will include Aboriginal participants' perspectives regarding positive and negative experiences and their recommendations for more effectively addressing educational issues regarding deafness.

I understand that my participation involves being interviewed by Heather on one or more occasions. Heather will ask me questions about my experience with educational issues regarding deafness. She may take notes and may use an audiotape or videotape during the interview. My comments may be used as part of her thesis. I have been assured that all information will be kept confidential and that my identity will not be revealed unless I give my written permission.

My participation in this study is voluntary and I may withdraw from the study at any time by simply telling Heather. I may refuse to answer any questions. I will receive answers to my questions about the study at any time. I will receive a copy of any transcripts for approval prior to analysis and I can make changes when misunderstanding has occurred. I will receive a copy of the thesis upon completion.

I understand that I can contact Heather Castleden at (780) 460 2258 at any time regarding this project. I can also contact Heather Castleden's advisors, Drs Peggy and Stan Wilson at the University of Alberta (780) 492 7625 regarding any concerns I have about Heather Castleden or the project.

I agree to participate in this project.

Interviewee: _____ Date: _____

Parent/Guardian: _____ Date: _____

Interviewer: _____ Date: _____

Please circle:
I do / do not wish my identity to be revealed in this thesis

## Appendix 4

**SCIENTIFIC RESEARCH LICENCE**

**Licence # 13083N**

**File # 12 410 564**

*ISSUED BY:* **Aurora Research Institute - Aurora College**
Inuvik, Northwest Territories

*ISSUED TO:* Ms. Heather Castleden
13 Piedmont Crescent
St. Albert, AB T8N 5E8
780-460-2258

*ON:* 07-Oct-99

*TEAM MEMBERS:* self

*AFFILIATION:* University of Alberta

*FUNDING:* Canadian Circumpolar Institute (CCI), Northern Scientific Training Program

*TITLE:* Deafness in northern Indigenous communities: Parent perspectives on supports and services

*OBJECTIVES OF RESEARCH:*

This project is intended to serve a multitude of people living in the NWT who are linked to one another by a singular issue - deafness. It will involve residents in the NWT through addressing issues fundamental to raising a child who is deaf. This will involve meeting with parents of deaf children, individuals who are deaf, community leaders, Elders, and professionals in the field of deafness to discuss the educational issues that a family and community experience regarding deafness. I have spent several years working in the deaf community and I am aware of the issues present in southern Canada. I am also aware that many of the supports and services are only available in the south thus the impact on Northern Indigenous families is significant. An analysis of the results and a set of recommendations will be developed in consultation with the research participants regarding the needs northern Indigenous families and communities have for accessing resources concerning deafness.

*DATA COLLECTION IN THE NORTHWEST TERRITORIES:*
*DATE(S):* January 1 - April 30, 2000
*LOCATION:* Yellowknife, Lutsel K'e

Licence# 13083 expires on December 31, 1999.
Issued at the Town of Inuvik on Thursday, October 7, 1999

Valoree Walker, Ph.D.
Science Advisor



TOTAL P.02